HIV Disclosure in 'Public' and Personal Spaces: A Mixed Methods Study of People Living with HIV in Khayelitsha, South Africa

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"*I am not worrying [about] the radio, but I am worried to go to talk [on] the TV. Everybody [will] look at me on the TV. But if I am going to talk to the radio I am not worried because those people didn't see me.*" (Dunyiswa)

"*So I told myself to that area where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can talk bad things outside about you... the feeling of disclosing to the community, you give yourself a lot of stress. Because if you walk, come out of your gate and you walk out in the street, you see the people making some funny jokes. So that thing can hurt you because you disclosed to them now they got stigma on you now.*" (Sylvia)

"*What Nokwanda is saying is that her community knows that she is HIV, because she disclosed to them….but because now she is well they don't believe anymore. So she doesn't understand why [the community thinks that] someone with HIV must have horns or look different.*" (Nokwanda translated by Sylvia)

"*Because they are the people that are close to me and they are the ones who were looking after me while I was sick, even though now they see that I am healthy. They need to know about what is happening and what has happened.*" (Nonceba)

"*Because if you tell after we do the sex, everything, maybe the condom breaks. Then he is going to the clinic to test. He is positive. So he is going to blame you. [Or] maybe someone knows you are HIV positive then he will hear you are HIV positive, then he is going to blame you, maybe he is going to kill you.*" (Dunyiswa)

"My last boyfriend didn't want to use a condom. When I say, "Hey, my doctor said I must use a condom because I am on antiretrovirals", and I was explaining everything to him. And he was like saying, "Go to the doctor and tell him he must use a condom to his wife." Like something like that. It was hard but I forced him. I said, "if you love me and you don't want me to leave, then we must use a condom." It's very difficult for them to understand. I mean they don't want condoms at all, they don't want. Men, they don't want condoms. But you have to try and try and try." (Lizeka)

"*It is important to disclose to your partner. Why not? Because in a relationship there are so many things that you share with your partner. So [many] beautiful things. I mean what is that person to you. Like you not giving the person the right to [say] how he feels. You don't know how he feels. You are just assuming that the person is going to react like that.*" (Thembi)

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Abbreviations

AIDS	Acquired immunodeficiency syndrome
ANOVA	Analysis of Variance
ARK	Absolute Return for Kids
ART	Antiretroviral therapy
ARV	Antiretroviral
ASRU	AIDS and Society Research Unit
ASSA	Actuarial Society of South Africa
CHC	Community health centre
CNS	Central nervous system
CSSR	Centre for Social Science Research
DALY	Disability Adjusted Life Years
FHH	Female headed households
GIPA	Greater Involvement of People living with AIDS
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research on Women
IVDU	Intravenous drug user
IDU	Injecting drug user
MSF	Medecins Sans Frontiers (Doctors Without Borders)
MSM	Men who have sex with men
NGO	Non-governmental organisation
NSP	New strategic plan
OLS	Ordinary Least Squares
PAWC	Provincial Administration of the Western Cape
PGWC	Provincial Government of the Western Cape
PCR	Polymerase Chain Reaction
PHC	Primary health clinic
PLWH	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
RSA	Republic of South Africa
SANAC	South African National AIDS Council
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TAC	Treatment Action Campaign
TB	Tuberculosis
UCT	University of Cape Town
UK	United Kingdom
UN	United Nations
UNFPA	United Nations Populations Fund
UNICEF	United Nations Children's Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
UK	United Kingdom
WHO	World Health Organization

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Abstract

HIV Disclosure in 'Public' and Personal Spaces: A Mixed Methods Study of People Living with HIV in Khayelitsha, South Africa

One of the most important and stressful decisions for people living with HIV (PLWH) is why, when and to whom to disclose their potentially stigmatised HIV status. Disclosure is simultaneously an act and a process which positions the HIV-positive individual at the nexus of a social context that will either support or stigmatise. In South Africa, where almost six million people are living with HIV, the need for disclosure is at multiple levels – for PLWH to access psychological, social and medical support, to reduce risky sex in relationships where one or both partners are HIV-positive, to combat negative perceptions of PLWH held by the general population, and to advocate for universal access to HIV treatment. Yet disclosure is also important because the impact of non-disclosure is significant, and includes poor care-seeking behaviours, risky sex, stress and mental health problems, amongst others. This research explores the dynamics of disclosure in public, private and intimate spaces.

The research used a multi-method approach including in-depth interviews, participant observation, and a structured longitudinal survey amongst the first cohort of patients on highly active antiretroviral therapy (HAART) through the public sector in South Africa. This is the first such comprehensive methodological approach to disclosure in South Africa. In the quantitative data, collected from 242 PLWH on HAART in Khayelitsha in 2004/5 and 2006, 100% of respondents had disclosed to at least one person and 42% reported that more than 50 people were aware of their HIV status. Disclosure to sexual partners occurred in all relationships reported by men (increasing over time) and 88% of relationships reported by women. No other study has found such high levels of disclosure amongst PLWH. Despite these high rates of disclosure, and an overall decrease in experiences of stigma over time, 36% of respondents reported experiencing at least one form of stigma in both surveys.

The qualitative data provide rich accounts of the multiple disclosure experiences of a group of HIV-positive women in Khayelitsha, who were part of an AIDS advocacy intervention entitled *LongLife* which included public disclosures of their 'HIV stories' for advocacy purposes. The narratives suggest that disclosure should not be conceptualised as a single act as PLWH may engage in multiple disclosures to various audiences in their lives, both privately and in more public settings. Public disclosure is mediated by audience-type, professional pressures, subjective constructions of community, and importantly, fear of the risks resulting from being identified as HIV-positive in their private lives. In the private space, disclosure is common within the household to carefully selected family members (mostly mothers and sisters), with respondents in the qualitative and quantitative studies indicating that they disclosed many times, to different people, with favourable responses for the most part. Depending on the audience and the stage of the disease, participants weighed up the risks of disclosure and their need for assistance. They disclosed for a range of reasons from self-interested motivations such as seeking health-care support, or other-interested reasons such as educating loved ones or challenging negative social attitudes towards PLWH.

The research found that disclosure within sexual relationships is highly complex with additional and profound risks and benefits to the individual, especially when it is women who are disclosing. Women are vulnerable to being blamed for 'bringing HIV into the relationship'

simply because they happen know their HIV status and made the first move to talk about sex and HIV. It is also stressful insofar as the discloser may be seeking some form of support or wanting to increase condom use – and there is a reasonable risk that this could result in rejection. Disclosure is also a mechanism for these women to increase control over their sexual lives – an on-going challenge in a gendered society where the general perception is that men are not trustworthy, negotiating condom-use is difficult and disclosure often leads to rejection. The multivariate analysis suggests that disclosure to sexual partners amongst women is driven by relationship dynamics such as cohabiting with partners, whether they know family members and whether the partner has had an HIV test – all indications of a positive intimate context with men experienced by few in the qualitative sample. Thus, this study suggests that the disclosure dialectic is not just between privacy and disclosure, but needs to be extended to include managing the dialectic between power and vulnerability – and between sexual agency and a social context that constrains and oppresses women.

The most common form of stigmatising behaviour found in both the qualitative and quantitative analyses is being gossiped about within their neighbourhood and community. One third of respondents in 2006 reported being gossiped about (decreasing from two thirds in 2004/5), demonstrating that gossip continues to be a significant problem for PLWH in Khayelitsha. The social costs of being gossiped about and publicly devalued remain a problem for PLWH, and especially for those who have disclosed more widely (usually as AIDS-activists), even after a number of years of public access to HAART. When they do disclose however, the respondents in the qualitative study speak of disclosure as a form of medicine; where antiretrovirals are a treatment for the HIV-infected body, and disclosure a treatment for the HIV-afflicted mind.

This study highlights the utility and importance of both the multi-method and multi-disciplinary approach to exploring complex behaviours such as disclosure within the context of both a stigmatised disease and a changing social context. Quantitative data is important for more generalisable findings, but it is often unable to capture the nuances of the experience of living with HIV, especially as experiences are determined by the changing nature of HIV disease and multiple and changing relationship dynamics over time with both family members and sexual partners. By using the multi-method approach to explore the experience of living with HIV through the lens of disclosure, the research shows that despite formidable challenges, PLWH play an active role in shaping the social and personal spaces within which they live.

Colin Almeleh, 2012

Chapter 1: Introduction

HIV/AIDS is an acute problem in South Africa where 5.7 million people are infected with HIV. This is 25% of total HIV infections in sub-Saharan Africa, and 17% of the 34 million people living with HIV globally (UNAIDS 2011; UNGASS 2010). In 2010, Sub-Saharan Africa accounted for 68% of all people living with HIV globally, a region with only 12% of the global population (UNAIDS 2011). Sub-Saharan Africa also accounted for 70% of all new HIV infections in 2010 (Ibid.). These considerable numbers point to the urgency and magnitude of the problem and the need to address the exceptional nature and impact of HIV/AIDS on society (Piot 2008) and South African society in particular (Navario et al 2010). But policy has to be designed in a way which takes account of the history, context and reality of HIV/AIDS in sub-Saharan Africa, in particular the ways in which millions of HIV-positive people continue to live with HIV in very challenging circumstances.

The HIV/AIDS epidemic and the experience of living with HIV/AIDS is as much socio-cultural, political and economic as it is medical. Since its discovery in the United States as a 'homosexual disease' in the early 1980s when it was termed Gay Related Immune Deficiency (GRID) to its recognition as a 'generalised' heterosexual epidemic in sub-Saharan Africa, HIV/AIDS has challenged and changed both global and local societies in unforeseen and unimaginable ways.

This dissertation comes out of my interest in the ways in which ordinary people living with HIV (PLWH) in South Africa reflect these challenges and changes in their everyday lives. Our understanding of these challenges, as they relate to the prevention of new HIV infections and the broader management of the huge number of PLWH in South Africa, is fundamental if society is to make progress in addressing the impact of the HIV/AIDS epidemic. As Peter Navario and colleagues note in their special report on HIV/AIDS in South Africa:

> "With 5.7 million infected people, South Africa remains the epicentre of the AIDS pandemic; the global AIDS fight cannot be won without a decisive victory in South Africa." (Navario et al 2010:2).

Many of these challenges facing PLWH in South Africa and in similar socio-economic and cultural contexts can be understood at the community and individual levels through focussing on the lived and subjective experiences of PLWH, and in particular through their experiences of disclosing their HIV-status to others. Disclosure is simultaneously an act and a process which positions the HIV-positive individual in a social context that will either support or stigmatise.

Through a multi-method research approach, using in-depth discussions, semi-structured interviews, participant observation, focus groups with and quantitative surveys of PLWH in Khayelitsha, South Africa, this project attempts to further our understanding of how PLWH develop innovative ways to cope with a dynamic disease and with changing social perceptions of the epidemic. Khayelitsha is Cape Town's largest African township and the site of the first public sector rollout of highly active antiretroviral treatment (HAART). Many people living there have thus experienced, either directly or indirectly, the physical and social dimensions of HIV disease – as well as the opportunities and challenges posed by life-long HAART. This thesis reflects these evolving sets of challenges and opportunities through the lens of HIV disclosure. It explores the negative social constructions of the virus as perceived and experienced by PLWH, the debilitating physiological effects of the virus and the life-changing and life-saving benefits of HAART, the impact of living with HIV on intimate relationships, and PLWH's interaction with their social sphere more broadly. It focuses particularly on HIV-positive women – those who bear the brunt of HIV infections in Africa.

The research explores the complexities of why and how people decide to disclose their HIV-status to others in order to access treatment, care and support but also to assist others in avoiding infection. It sheds light on the linkages and relationships between the biological, the social and the individual contexts. In so doing, it touches on constructions of risk in relation to disclosing publicly; the influence of popular perceptions of HIV/AIDS and the sources of these perceptions; and the nature of sexual relationships in contemporary Khayelitsha and the impact of HIV on sexual relationships where at least one partner is HIV-positive. It is important to point out upfront that this research does not look at disclosure of HIV-status by parents to children, nor does it look at the impact of HIV/AIDS on children in general. Disclosure to children (and the consequences of having a parent living with or having died from HIV/AIDS) entails very different dynamics compared with inter-adult disclosure and merits a thesis in and of itself (see e.g. Cluver and Orkin 2009; Richter, Stein and Cluver 2009).

A key finding from this research is that the personal and social contexts revealed through the experience of disclosure are varied and that the conventional wisdom which holds that PLWH are in a constant battle against a society that automatically stigmatises, a society in which people (especially women) are powerless, and a society where personal strategies for survival and happiness are unlikely – is misplaced. By exploring disclosure through mixed (quantitative and qualitative) methods, the dissertation reveals some of the psychological and sociological aspects of this bio-psychosocial disease that often remain hidden.

The dissertation is structured as ten chapters. The beginning chapters contextualise the research study, at the macro level in terms of South African society and Khayelitsha, and more broadly, the global AIDS epidemic and the feminization of the African AIDS epidemic in particular. The content is structured according to the broad disclosure audiences that were analysed: public; family and friends; and sexual and intimate partners. The analyses of the various audiences are categorized in such a way as to reflect the very different kinds of risks that need to be considered and managed, and the relevant levels of trust required when disclosing to the various audiences and support systems in the lives of PLWH. Furthermore, through focussing on disclosure in the public domain first, which includes an analysis of the social context of HIV, the chapters that follow on the more private dynamics of disclosure are appropriately located in the social context.

The first substantive chapter (Chapter 2) describes the global AIDS epidemic, the feminization of HIV/AIDS, and HIV/AIDS in contemporary South Africa. It first describes the epidemic in general and the ways in which women have been disproportionably affected by HIV/AIDS. It then moves on to describe how South Africa attempted to address the impact of HIV/AIDS with limited success in the earlier years of the epidemic under the presidencies of Nelson Mandela and Thabo Mbeki. It then describes the HAART rollout in South Africa with particular reference to the nature of the rollout in the Western Cape and Khayelitsha, as over 60% of the first cohort of HAART patients in Khayelitsha are in the quantitative sample.

Chapter 3 describes and discusses relevant theory and literature that are used to frame aspects of the analysis in the later chapters. It pays particular attention to conceptual notions of modern risk, Communication Privacy Management, and AIDS-related stigma[1] as theoretical frameworks for analyzing the dynamics of disclosure. The chapter draws on key features of

[1] The popular term 'AIDS-stigma' or just 'stigma' will be used throughout the dissertation in place of the more correct, but cumbersome, term - HIV/AIDS-related stigma.

these theoretical frameworks to highlight how the experience of living with HIV is at the same time a personal, physical and social experience. The chapter also problemitises a significant body of research that views disclosure exclusively through the stigma lens, and argues that the stigma lens places a bias on the understanding of living with HIV as a purely negative experience.

Chapter 4 describes the study location, the research methodologies and data used in the research (qualitative and quantitative). As important contextual information for the analysis that follows, the chapter describes the history and socio-economic context of Khayelitsha both as the location of the study but also as the site of the first public sector rollout of HAART in South Africa (and consequently a heavily contested space for AIDS-advocacy). The contextual information provides useful background for the data analysis that follows, as despite not being generalisable to the whole of South Africa in terms of sample size, gender and the uniqueness of Khayelitsha, the study participants are an important sample in terms of the history of the South African response to the AIDS epidemic.

Chapters 5 through 9 present the study's findings in detail, beginning with a quantitative analysis in Chapter 5 on stigma to provide general context, moving to the in-depth qualitative analysis in Chapters 6 through 8 on disclosure in public, private and intimate spaces, and then returning to the quantitative analysis of disclosure in Chapter 9. Chapter 5 uses quantitative survey data on stigma from the KSPS 2004/5 and 2006 surveys amongst PLWH on HAART in Khayelitsha. It does not seek to analyse the determinants of stigma, but rather to present a broad over-view of the experiences of stigma reported by survey respondents and the relationship between stigma and disclosure. The aim of the chapter is to contextualise the subsequent more nuanced and detailed analysis of stigma and disclosure as experienced and challenged by respondents in the qualitative part of the study.

Chapter 6 describes the experiences of the qualitative respondent group who disclosed their status publicly as part of the *LongLife* advocacy intervention. Using in-depth interviews and extensive participant observation between 2003 and 2006, the chapter describes and analyses the women's public disclosure experiences, and through locating these public disclosures in the wider context of what was happening in South Africa during this period in time, sets the broader social context for the following chapters that are based on inter-personal experiences of disclosure with significant others (household members) and sexual partners.

Chapter 7 presents the results of the qualitative analysis of disclosure to significant others (mostly household members and friends). This chapter explores a range of experiences of disclosure amongst the group of women and unpicks the ways in which the social, individual and physical experiences of living with HIV interact. Chapter 8 presents the analysis of disclosure to sexual partners and sexual relationships. It describes and discusses the sexual relationship and disclosure narratives of the same group of women analysed in Chapters 6 and 7, and highlights the ways in which living with HIV complicates an already complicated experience of sexual relationships and men in general amongst women in Khayelitsha.

The quantitative data used in Chapter 9 returns to the experiences of disclosure amongst the wider population using the analysis from the qualitative chapters that come before as context to understand general disclosure experiences, rates and correlates. The quantitative data also allows for an exploratory analysis of the correlates and determinants of the complexities of disclosure within sexual relationships. Following from the discussion in Chapter 6 on public disclosure, Chapter 9 also uses the survey data to explore the determinants of public disclosure amongst the sample of people PLWH on HAART for greater than one year (i.e. stabilised on treatment).

The final concluding chapter synthesizes the findings of both parts of the study, namely the qualitative and quantitative analyses, and discusses the results with specific reference to the methodologies that were used. Some of the parameters of the qualitative work and limitations of the quantitative study are outlined. This chapter presents concluding remarks and considers the implications of the study's findings.

Chapter 2: Setting the context

2.1 Gender and the African AIDS epidemic

Over twenty-five years into the African AIDS epidemic, it has become clear that HIV/AIDS is a disease which affects women in particular, and that its socio-economic dimensions vary (e.g. Iliffe 2006; gender and poverty are consistent themes in UNAIDS World AIDS Day Reports see UNAIDS 2006; 2007; 2008; 2009). In the 1980s when HIV was first isolated, HIV was viewed as a disease of homosexual men (or as more recently termed, men who have sex with men (MSM)), largely as a result of the rapid spread of the virus through the US East coast community of gay men (Barre-Sennousi et al 1983; Gallo et al 1984; Gallo and Montagnier 2003; Gottlieb et al 1981). The epidemic then made its way into the injecting drug use populations, again mostly in developed economies – but also subsequently in Asia. But in Africa, where the disease likely originated from zoonotic transmission from apes to humans (Sharp and Hahn, 2010), HIV is spread heterosexually, with women being especially vulnerable to infection (Iliffe 2006, UNAIDS, 2004a; 2004c). In terms of the global AIDS epidemic, it appears that it is the economically and socially disadvantaged who are most vulnerable to infection and who bear the biggest brunt of the impact of the AIDS epidemic (Whiteside, 2002). In Sub-Saharan Africa, however, there is a lively debate about the relationship between economic and behavioural factors (notably multiple and concurrent relationships) in driving the HIV epidemic (see e.g. Sawers and Stillwaggon 2010a, 2010b and Nattrass 2009, Epstein and Morris 2011, Goodreau, 2011).

As of December 2010, the number of PLWH globally totalled 34 million, with 2.7 million new infections and 1.8 millions AIDS-deaths in 2010 alone (UNAIDS 2011). Of these, 31.3 million were adults and 2.1 million were children under 15 years (UNAIDS 2010). Women make just over half (50.2%) of all infected adults up from 48% in 2007, a proportion which rises to almost 80% in the epicentre of the pandemic in Sub-Saharan Africa (Ibid.). Home to only 12% of the world's population, 67% of PLWH and 80% of all HIV-infected women reside in sub-Saharan Africa (ibid.). Even though reductions in incidence has caused global HIV prevalence to level off, the number of people living with the disease continues to rise due to failures of prevention campaigns in certain regions and the life-prolonging effects of HAART (Ibid.).

In South Africa, the country with the largest number of PLWH in the world (5.7 million according to ASSA 2003 and 5.2 million according to the government statistical agency (STATS SA) and the Human Sciences Research Council (HSRC[2])), the impact of the epidemic among poor women is even more pronounced (Brandt 2006). According to the South African National HIV Prevalence Survey, HIV prevalence amongst 25-29 year old women was 32.7% compared to 16.7% amongst men of the same age group (Shisana *et al*, 2009). Women also account for a higher proportion of deaths due to AIDS than men (33.8 versus 29.8%) (Bradshaw *et al*., 2003). Furthermore, overall, one in five South African (adult) women are HIV infected (Shisana *et al*., 2005). A higher prevalence for African adult women (24.4%) compared with women in general (20.2%) also reflects the high representation of poor women given that the African population represents the poorest sector of South African society (ibid.).

There is strong evidence that women, especially young women, are more vulnerable to HIV infection than men which gives rise to the statistics shown above. As discussed below, part of the explanation is biological as women are physiologically more vulnerable to HIV infection during heterosexual sexual intercourse (Glyn et al 2001), and part is behavioural through contextual factors such as the tendency for younger women to have older sexual partners (Pettifor et al 2004). This, in turn, is structured by broader patriarchal social relations (Campbell et al 2006; Leclerc-Madlala 2002). Importantly, because of women's increased social and biological vulnerability to HIV, it has been shown in a number of studies that it is often the woman rather than the man who is HIV-positive in discordant couples – known as female discordant couples (de Walque, 2007; Mishra et al., 2007).

From a biological perspective, women are between two and four times more likely than men to contract HIV from a heterosexual sexual encounter (Aberg 2005). Several reasons can be given for this difference. Reasons for the additional biological vulnerability of women include: higher concentrations of HIV in semen than in vaginal fluid; the larger area of exposed female than male genital mucosal surface area; the longer period of exposure of semen in the vaginal tract; and the greater permeability of the mucous membranes in the vagina compared to the penis (see also WHO 2000; Cohen et al 2010). Additionally, pre-existing and undiagnosed sexually transmitted infections (STIs) increase the chance of infection and are more likely in women

[2] Estimates of people living with HIV in South Africa vary with STATS SA and HSRC both estimating HIV prevalence at 5.2 million people (Mid-Year population estimates 2009 and SA National Prevalence, Incidence, Behaviour and Communication survey 2008, respectively); while the ASSA 2003 model estimates HIV prevalence at 5.7 million (SA UNGASS Report 2010:10). http://www.unaids.org/en/regionscountries/countries/southafrica/ accessed 13/03/2011

given that STI symptoms are less apparent thereby delaying detection and diagnosis (Karim and Karim 2005: 194).

Beyond the biological vulnerability of women to HIV infection, the ways in which gender inequalities operate at a societal level in developing countries to reinforce prevailing power structures in which men dominate women have been well documented and described (see e.g. Farmer 1996; Jewkes et al 2006; Lewis 2005; Stillwaggon 2006, Walker and Gilbert 2002; Rao-Gupta 2004; Karim and Karim 2005).[3] Prevailing cultural norms, particularly in the patriarchal cultural contexts prevalent in countries in sub-Saharan Arica, construct women as inferior and dependant (see e.g. Kambarami's 2006 study of Shona women in Zimbabwe). Women are often treated as inferior to men, barring them from inheritance and independent financial decision-making (Seekings 2008; Rao-Gupta, Whelan, & Allendorf, 2003). As Maureen Kambarami notes with reference to the Shona in Zimbabwe:

> "In the Shona culture, once a girl reaches puberty all teachings are directed towards pleasing one's future husband as well as being a gentle and obedient wife. Her sexuality is further defined for her, as she is taught how to use it for the benefit of the male race. Furthermore, these cultural teachings foster a dependence syndrome this is why most African women depend heavily on their husbands for support. As a result, once a husband dies, the woman quickly remarries so as to find another pillar of support to lean on" (2006:3)

Similarly, Jonathan Mann (the former head of the WHO's Global AIDS Program) asserted:

> "The central problem of HIV in women can't be solved with posters, information campaigns or condom distribution. The central issue isn't technological or biological: it is the inferior status or role of women. To the extent that, when women's human rights and dignity are not respected, society creates and favours their vulnerability to AIDS." (UNAIDS 1998)[4]

A significant body of literature that explores the impact of HIV/AIDS in sub-Saharan African argues that the vulnerability of women due to existing socio-cultural and economic factors,

[3] See www.icrw.org for literature on the gendered impacts of HIV/AIDS and poverty in developing countries. See also UNAIDS et al (2004) for a summary of the what UNAIDS calls "the triple threat of gender inequality, poverty and HIV/AIDS" (2004: iv) - http://www.unfpa.org/upload/lib_pub_file/308_filename_women_aids1.pdf
[4] http://www.undp.org/rblac/gender/aidsgender.htm#top

specifically within sexual relationships, is exacerbated by HIV/AIDS (e.g. Africa Region Gender Team, 2000; Brandt 2006; Farmer et al 1996; Gupta, Whelan, & Allendorf, 2003; UNAIDS, 2004c), but is also evident in studies of low-income populations in industrialised countries in Europe and the USA (Sobo 1995; Buseh and Stevens 2006; Gielen et al 2000; Simoni et al 2000).

Male dominance can be manifested in sexual violence against women (Jewkes et al 2006). This, as well as men having multiple sexual partners significantly more often than women (Mishra and van-Assche 2009) – another sign of patriarchal norms – puts women at an elevated risk of HIV infection (Jewkes et al 2006; Campbell 1995). In a survey conducted by Kalichman et al (2007) with 435 men in a township near Cape Town, the researchers found that more than half of their sample held hostile attitudes towards women and believed that violence against women was legitimate (2007: 26). Over 20% of men in the survey admitted to using force or threatening to use force to gain sexual access to women. Such statistics are supported by evidence from other studies in townships in and around Cape Town (see Kalichman and Simbayi 2004; Wood and Jewkes 1997).[5] Kalichman and Simbayi (2004) reported that 40% of women surveyed had been sexually assaulted in adulthood.[6] These 40% were also more likely to have had sex in exchange for material goods, have multiple sex partners, greater rates of unsafe sex, and more sexual encounters during menstruation (Kalichman and Simbayi 2004: 687). Studies from outside South Africa (e.g. Pettifor et al 2004 in Zimbabwe) have also found high rates of young women having their first sexual encounter with older men. Rachel Jewkes and her colleagues' research with sexually active women aged 15–26 from 70 villages in rural South Africa found that 26.6% of their sample had experienced more than one episode of physical or sexual intimate partner violence (2006: 1461). In 2009, Jewkes and her colleagues again produced some astonishing figures from their research amongst mostly young men in three districts in KZN and Eastern Cape in South Africa, where rape of a woman or girl had been perpetrated by 27.6% of the men interviewed (Jewkes et al 2009). However, Southern African surveys which collect data on gender-based violence and HIV status do not always reveal statistically significant correlations between the two variables (e.g. Ngwaru 2009).

[5] Neither Kalichman and Simbayi 2004 nor Kalichman et al 2007 report the name of the townships in which the surveys were conducted.

[6] Despite these reports and general high domestic violence statistics, the HAART survey data (see Chapter 9) found very few accounts of being coerced or forced into having sex, with only 2.67% (n=6/225) reporting that they had sex while being physically forced, hurt or threatened or coerced.

A possible further contributor to women's vulnerability is the fact that so many are single and/or in unstable relationships. In the Khayelitsha survey data used later on in this study, the majority of the participants are unmarried women. This is consistent with the broader social context, which has seen declining marriage rates and a rise in single person households, a social phenomenon that Mark Hunter attributes in part to rising unemployment and increased female rural-urban migration (Hunter 2010; see also Seekings 2008). Hunter (2010) argues that single women in unstable or casual sexual relationships are especially vulnerable to HIV infection (see also Hargreaves et al 2009), but others point out that women in longer-term relationships are also vulnerable (Parikh 2007). There is no simple correlation between relationship-type and vulnerability to HIV-infection.

In post-apartheid South Africa, women are confronting the HIV epidemic at a time where they have increased access to employment, housing and public grants, but diminished access to social resources such as social support through kin through the decline of marriage and patrilinearity (Seekings 2008:7). Thus both the familial and intimate contexts for individuals are in flux. These social processes could potentially be seen as part of a broadly defined type of individualisation attributable to the movement of South African society towards a variant of 'modern risk society' as described by Heinrich Beck and Anthony Giddens in their influential research on post-industrial Europe (see Chapter 3 for a more detailed discussion on South Africa, HIV/AIDS and Risk Society). And, to the extent that managing risk entails agency, this approach highlights the strategic dimension to human behaviour, which in the context of gender relations in particular, frames women as actors in a socially constrained environment, rather than as merely passive and oppressed victims. In this respect, it dove-tails with evidence from Malawi which highlights female agency – including in reshaping social norms around HIV and gender relations (e.g. Swidler and Cotts-Watkins, 2007)

Studies which focus exclusively on women's vulnerability and dominance by patriarchal norms are limited by the implicit lack of agency given to women, and by their blunt and undifferentiated approach to sexual relationships. While it is important to acknowledge women's vulnerability, over-emphasising it runs the danger of missing the key ways in which – as Susser and Stein showed as far back as 2000 – women are active participants in their relationships especially around risk prevention, even within relationships that are profoundly

shaped by patriarchal cultural forces (2000:1048).[7] Equally, approaches which concentrate only on power differentials in sexual relationships may also miss the ways in which some women's behavioural strategies for them as individuals both put their own and their partner's health at risk, yet are rational strategies in specific relational contexts and at specific times (Parikh 2007; Zembe et al 2011). For example, Zembe et al (2011) reported from their research in a township near Cape Town that women interviewed described their initiation of sexual relationships "in a hunting, predatory manner" (ibid.:3). Further, the researchers report that even though the same women report high levels of intimate partner violence, they nevertheless claim to exploit older men for financial gain while seeking younger males for sexual gratification (ibid.).

All too often, HIV/AIDS researchers fail to ask the difficult questions that explore the complex and changing ways in which women are simultaneously bounded by, contest and shape social norms. Research is thus limited in its understanding of the ways in which women's choices influence their relationship outcomes, and the strategies by which women manipulate or demand certain desired behaviour from men. As discussed in Chapter 8, such a dearth of critical thinking is evident in the many studies that focus on women's disclosure in sexual relationships and their difficulties in negotiating condom-use, which fail to problemitise the relationship between structure and agency.

2.2 HIV/AIDS in South Africa

Historically, it is important to tell the story of living with HIV in the late 20th and early 21st century in South Africa, particularly in a place like Khayelitsha. Khayelitsha was on the frontline of both the national and global fight for the rights of PLWH to obtain access to PMTCT and HAART (Hodes and Holm-Naimak 2012). This dynamic almost certainly influenced the experience of living with HIV and disclosure in both positive and negative ways. For the benefit of PLWH, there were numerous avenues of support (notably the Treatment Action Campaign (TAC) and Medicins sans Frontiers (MSF)) that could be tapped into by PLWH. However, such a ground-swell of activism and support also pressured individuals living with HIV to be willing and open to disclose their HIV status in both private and public contexts in order to contribute to the fight for the normalisation of HIV and for increased availability and access to services – services that were denied to most for a number of

[7] Susser and Stein conducted their research in the early nineties in five sites around Southern Africa. The site selection aimed to reflect "urban and rural experiences, various populations, and economic and political opportunities for women over the course of the HIV epidemic" (2000:1042).

years. Thus, the experiences of disclosure analysed in this thesis are likely to be context-specific and that different challenges likely face PLWH disclosing their HIV status in other contexts and countries, in particular those countries with a weaker influence of civil society.

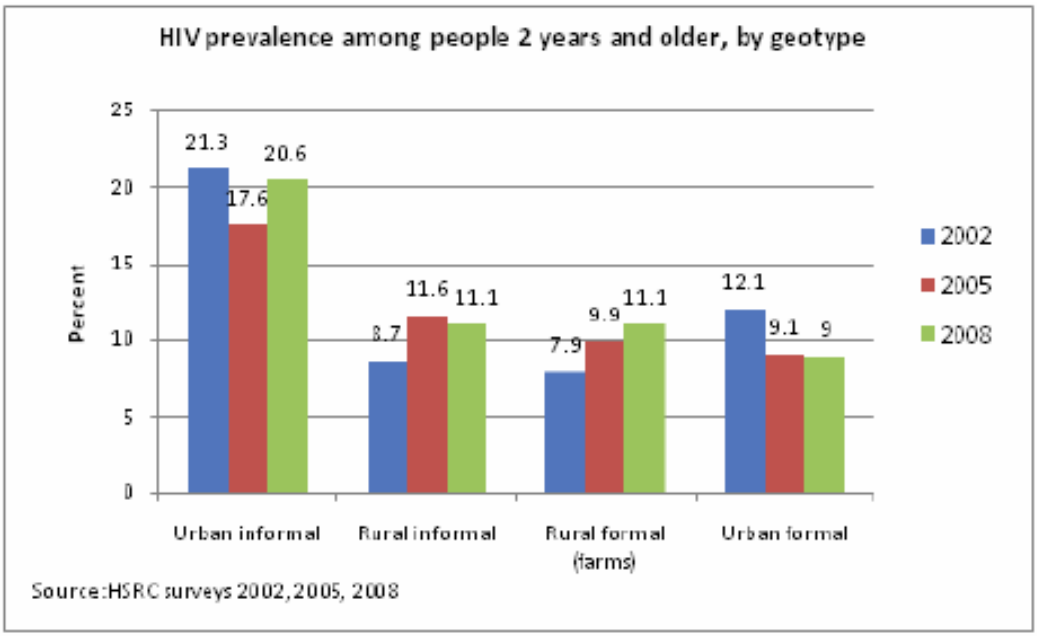
Khayelitsha played a central role in the dramatic changes in the South African HIV/AIDS environment, leading up to the watershed moment in late 2009, on President Jacob Zuma's first World AIDS Day in office[8], where the South African state emphatically distanced itself from ex-President Thabo Mbeki's AIDS denialism and began making ambitious plans for universal access to HAART. The research for this study was conducted between 2003 and 2006, four years prior to these changes and within a vastly different context for PLWH. These years were personified by very different events in the history of South Africa, particularly the poor political leadership on HIV/AIDS by President Thabo Mbeki and his Health Minister Manto Tshabalala-Msimang (Nattrass 2007). Key contextual features of this time included: limited access to prevention of mother to child transmission (PMTCT) and antiretroviral treatment (ART) services; the civil disobedience campaign by the Treatment Action Campaign; numerous court cases between civil society and the South African government; the embarrassment of South Africa at the International AIDS Conference in Toronto; the promotion of untested remedies for HIV such as *Uhbejane*[9], amongst many other shameful and sad episodes (see e.g. Nattrass 2007; 2008, Geffen 2010).

However, even though there have been significant changes in the South African AIDS context, in particular the removal of Thabo Mbeki and Manto Tshabalala-Msimang[10] from the political arena and the increase in number of people accessing HAART, stigma and discrimination of PLWH remain a problem (Maughan-Brown 2009, 2010; Visser et al 2009; Gilbert and Walker 2009). In his research amongst young adults aged 14-22 years in Cape Town between 2003 and 2006, Maughan-Brown (2010) found that stigma appears to have increased over the period – during the same time as the first public sector pilot HAART program began operating in Khayelitsha and despite the fact that this group of young people were likely to have been a highly targeted group for prevention messages (ibid.). This evidence should make one wary of drawing automatic links between the provision of HAART and reduction in stigma. Thus, even in the context of a stronger national rollout of HAART, fear of stigma continues to persist as a factor affecting disclosure today.

[8] See a transcript of President's Zuma's speech at http://www.info.gov.za/speeches/2009/09120112151001.htm
[9] See http://www.health-e.org.za/news/article.php?uid=20031380 accessed 28/03/2007
[10] Manto Tshabalala-Msimang died in December 2009. She was Minister of Health from 1999 to 2008.

According to estimates from the ASSA2003 demographic model (South Africa's leading AIDS demographic model),[11] in 2006, 18.3% of South African adults and 11.2% of the total population were HIV-positive. These estimates are consistent with national survey data produced by the HSRC (2008) where they estimate that 5.2 million people are living with HIV in South Africa (slightly less than the 5.7 million estimated by UNAIDS/WHO). The third South African National HIV, Behaviour and Health survey for 2008 (see below), shows that there has been a consistent distribution between the three national surveys of HIV-prevalence according to geo-type with the highest prevalence consistently recorded in urban informal settings – like Khayelitsha (HSRC 2008).

Figure 2.1 HIV prevalence among people 2 years and older from 2002 - 2008



At the time of the survey research in 2004, just over 200,000 people had access to HAART in South Africa (Nattrass 2006b), less than 40% of those in need according to World Health Organisation (WHO) treatment guidelines at the time which stated that PLWH with either clinical Stage 4 HIV disease symptoms (i.e. had AIDS) or with a CD4 cell count of < 200/mm^3 should begin HAART immediately.[12] Cross-country comparative research showed that South Africa's performance was disappointing in this regard both in absolute terms – and relative to the achievements of other countries (Nattrass 2008b). In his book, *Race Against Time*, Stephen

[11] The ASSA2003 model and summary statistics can be accessed on www.assa.org.za. The ASSA 2003 model is so named to indicate that the most recent antenatal clinic survey data used is from 2003.
[12] HAART guidelines have since changed to recommending HAART initiation at a CD4 count of < 350/mm^3 (WHO 2009)

Lewis (the UN Special Envoy for HIV/AIDS in Africa) stated:

> "Over the last four years, I have been to every country in East and Southern Africa, many of them two, three and four times. I can say confidently and categorically that every single country (with the exception of newly peaceful Angola, whose borders were closed to traffic–and the virus–throughout the civil war) is working harder at treatment than is South Africa, with fewer relative resources, and in most cases nowhere near the infrastructure or human capacity of South Africa. It is a situation which is absolutely mystifying. (Lewis 2005: 187)

Zanakis et al (2007) have shown that South Africa was 'inefficient' in HIV prevention (i.e. given her economic and institutional resources, HIV prevalence should have been lower) and Nattrass (2008b) has shown that given South Africa's level of development, access to HAART should have been a lot higher. This has been attributed to Mbeki's suspicions towards HIV science and antiretrovirals in particular (Nattrass 2007, 2008a; Geffen 2010). Recent research suggests that such suspicions continue to reverberate amongst young people in Cape Town, with adverse implications for HIV prevention (Grebe and Nattrass 2011).

2.3 Antiretrovirals in the Western Cape: The Khayelitsha ARV rollout

South Africa has a decentralised system of government which gives some autonomy to provincial governments. The Western Cape government, which differs from the other provinces in having very strong opposition parties, was the first South African province to introduce ARVs for the prevention of mother-to-child-transmission (PMTCT) of HIV. In January 1999, PMTCT was made available to HIV-positive pregnant women in Khayelitsha. The Health Department of the Provincial Administration Western Cape (PAWC) started the PMTCT programme in two maternity obstetric units in Khayelitsha (Abdullah, 2005: 249). In addition to providing ARVs for PMTCT to HIV-positive pregnant women, the Western Cape Government set up a voluntary counselling and testing (VCT) service at two maternity units that resulted in the annual number of HIV tests being conducted in Khayelitsha rising from 450 in 1999 to 22,000 in 2005. As Table 2.2 shows, the focus on Khayelitsha as the first district to receive HIV services was certainly appropriate considering the high adult HIV prevalence compared to other districts within the province.

By May 2001, other government clinics in Khayelitsha, in collaboration with MSF, notably

Michael M, Site B and Site C, began to offer HAART to people with advanced HIV disease (Kasper *et al.*, 2003). This pilot project demonstrated that PMTCT and HAART programmes could be operationalised even in poor communities with successful patient outcomes (Coetzee *et al*, 2004). As a result of these pilot programmes in the three clinics, the programme expanded to more than 300 antenatal and child health clinics in 2001 (Abdullah, 2005: 249), and it has since then reduced mother to child HIV transmission rates (MTCT) down to less than an estimated 3.5% (MRC 2011[13]).

Table 2.2: Antenatal HIV prevalence in the City of Cape Town

Antenatal HIV prevalence in the Cape Metropole District, 2003 – 2005 including range (±)					
Area	**2001 (%)**	**2002 (%)**	**2003 (%)**	**2004 (%)**	**2005 (%)**
Blaauwberg	0.6±1.1	8.2±6.0	4.4±3.0	1.2±1.0	7.3±3.6
Cape Town Central	3.7±3.6	11.9±6.0	11.6±5.0	13.7±4.7	11.5±3.3
Greater Athlone	6.8±4.6	8.9±4.0	10.1±4.4	16.4±3.6	17.7±3.5
Helderberg	19.0±6.0	19.1±4.5	19.1±4.2	18.8±3.3	12.8±3.0
Khayelitsha	22.0±5.0	24.9±4.2	27.2±4.2	33.0±3.5	32.5±3.2
Mitchells Plain	0.7±1.3	4.0±4.0	6.3±4.0	12.9±3.5	5.1±2.0
Gugulethu / Nyanga	16.1±6.5	27.8±5.2	28.1±4.2	29.1±2.8	29.1±3.9
Oostenberg	5.7±3.3	14.5±6.0	16.1±4.3	14.8±3.3	16.2±3.5
South Peninsula	5.9±3.9	6.0±4.1	9.3±3.8	10.8±3.2	12.4±3.2
Tygerberg Eastern	6.1±3.4	10.4±5.0	7.9±3.9	12.7±3.6	15.2±3.5
Tygerberg Western	7.9±3.9	12.7±5.0	8.1±3.3	15.1±4.0	15.0±3.2
Provincial Total	**9.2±1***	**12.2±1***	**12.6±1.2***	**14.8±1.2***	**15.03***

Source: The 2005 Provincial and Area HIV Surveys: Western Cape (DoH 2005)

*Weighted provincial estimates derived from the collated Area HIV Surveys

The HAART programme was initiated to demonstrate its feasibility in a primary health care setting and in a resource-limited environment. Extensive research has been conducted on this programme in Khayelitsha (see e.g. Coetzee et al 2004; Coetzee et al 2005; Boulle et al 2010, Hodes and Holm Naimak, 2011). In addition to providing HAART, the programme also provided VCT and treatment for opportunistic infections. Initially the programme was almost exclusively run by MSF with support from other civil society organisations (TAC in particular), however the provincial government and relevant clinics gradually started to take over the programme to ensure sustainability of service delivery. Shortly after the introduction of MSF's programme in Khayelitsha, the Desmond Tutu Foundation set up a clinic in Gugulethu, followed shortly by other international NGO or research-based initiatives in public

[13] http://www.mrc.ac.za/pressreleases/2011/10press2011.htm accessed 14 July 2011

health facilities within the Western Cape. By the end of 2003 the Western Cape Province had established HAART sites in the Langa clinic, GF Jooste Hospital, Groote Schuur Hospital, Tygerberg Hospital and Red Cross Hospitals in addition to the Gugulethu clinic and the three Khayelitsha clinics (Abdullah, 2005: 250).

The progress made by the Western Cape government, MSF and others should be viewed in the context of the ground-swell of popular mobilisation around HIV/AIDS largely driven by the TAC working with other actors such as MSF and the AIDS Law Project (see e.g. Geffen 2010; Grebe 2011). The influence of TAC on the individual, social and political context of HIV/AIDS will be discussed in more detail in Chapter 6. The key issue for this research is that the combination of international actors in organisations such as MSF, the positive action and leadership of the local Western Cape government and the grassroots support for PLWH from others living more openly with HIV (through public HIV disclosure and the wearing of the 'HIV-positive' T-shirt for example), had a significant influence on the broader context for PLWH in Khayelitsha (Grebe 2011).

During the period in which qualitative and quantitative data was collected (from late 2003 to 2006) the social, political and medical context for PLWH underwent profound changes. Some of the respondents interviewed as part of the study were actively involved with TAC, others not. Some even went as far as aligning their personal struggles with that of the broader fight for HAART by involving themselves with projects entailing public disclosure of their HIV status and TAC's civil disobedience campaign (see Chapter 6). In a January 2012 conversation with Thobani (one of the fieldworkers for the surveys), he stated that his current struggles 12 years after his HIV diagnosis are related to 'normal' life such paying school fees for his son and recovering from a car accident, and that his life is no longer dominated by HIV. At the time when the research was conducted, he said that he and many other PLWH in Khayelitsha were more political because they were fighting for AIDS treatment (Personal Communication 27/01/12). But no matter what the level of political involvement, all had to confront the challenge of disclosing their HIV status to friends, sexual partners and households – a challenge which changed as they gained access to HAART and as HAART became a more accepted and common part of the social and biomedical context in Khayelitsha.

Chapter 3: Disclosure, risk and stigma: theory and literature

It is common cause that the AIDS epidemic in sub-Saharan Africa has been exacerbated by the social and cultural dimension of HIV/AIDS, in particular the high levels of stigma and discrimination which by all accounts create barriers to prevention, treatment, care and support for those already infected (e.g. Aggleton et al 2005; UNAIDS 2006). A WHO/UNAIDS press release on the release of the progress report (WHO/UNAIDS 2006) for the '3 x 5' global treatment initiative (to put 3 million people on treatment by 2005) quoted the past UNAIDS Executive Director Peter Piot as stating: "Misinformation about the disease and stigma against PLWH still hamper prevention, care and treatment efforts everywhere."[14] The International Treatment Preparedness Coalition (ITPC) reported stigma to be a major hindrance to the scale-up and success of universal access to HAART and that "pervasive stigma against people living with HIV/AIDS requires moral leadership from national and global communities" (ITPC 2005:7). Such leadership was certainly lacking in the South African national context (Nattrass 2007, 2008b), and stigma (or the fear of it) continues to play a role in the lives of PLWH (Gilbert and Walker 2009).

However, 'stigma and discrimination' has been used to describe almost everything that forms a barrier to successful public-health and prevention campaigns, and to appropriate treatment, care and support for PLWH, often with limited evidence in support of these assumptions (Reidpath and Chan 2006). Deacon et al (2005: ix) refer to this as 'conceptual inflation', a termed first coined by Miles (1989) in his seminal work on racism. As Deacon et al (2005) point out; this 'conceptual inflation' has blurred a much-needed intricate understanding of the underlying social context in which stigma exists, where poverty, politics, history, culture, globalisation and inequality are contributing factors. Defining and understanding stigma is central to understanding the experience of living with HIV/AIDS. However, there are other important factors that also require equal or sometimes greater emphasis. Importantly, insufficient attention has been paid to the *dynamic* relationship between the individual, the socio-cultural and the physical spheres of people's experience of living with HIV (i.e. the changing manifestations of HIV disease itself). This dissertation explores these issues through the lens of HIV disclosure and draws on insights from different disciplines both theoretically and methodologically. In this Chapter, I review the academic theoretical literature most relevant for this exercise.

[14] www.who.int/**hiv**/mediacentre/news57/en/index.html accessed 1 April 2006

3.1 Towards a multi-disciplinary approach

Social theory has only recently been used as a tool to understanding the AIDS epidemic (Seckinelgin 2007). As of the late nineties, social scientists began engaging with AIDS as a social, structural as well as a biological issue (Ibid.; Farmer, 1992, 1999; Treichler 1999). It is illustrative to discuss some of the reasons for this inaction or 'late action' on the part of social scientists and to focus on the weaknesses of social theory as it has been applied to AIDS in sub-Saharan Africa.

The limited development of social theory on AIDS likely originated in the widespread perception that AIDS was an emergency, requiring immediate action informed by more practical and empirical approaches than typically provided by sociological approaches to methodology, theory and research (Seckinelgin 2007). Indeed, conceptions of AIDS have been dominated by public-health, epidemiological, psycho-behavioural and biomedical discourses (Treichler 1999; Bujra 2000), leading to an overriding focus on the individual. Campbell (2003) attributes the prioritisation of individualistic and behavioural perspectives to the fact that the academic field of the social science of HIV/AIDS has been largely dominated, in practice and research, by psychologists who tend to favour individual-level conceptualisations of the causes of health-related behaviour.

Such individualistic approaches have some limitations when it comes to understanding the social context of AIDS and the socially constructed aspects of the way people respond to AIDS. Firstly, these models have been found to have limited in explanatory power due to their individualistic nature, which conceptualises the individual as a "rational information-processor, whose behaviour is determined by a combination of psychological factors such as individual attitudes, personal action plans and perceived social norms" and ignores the influence of socio-cultural, structural and physiological factors (Campbell, 2003:8). Researchers within the South African context (e.g. Campbell, 2003; Eaton, Flisher and AarØ, 2003) have argued that while these models may have much utility in the developed world, in marginalised communities with high HIV-prevalence (such as Khayelitsha) the socio-cultural context is potentially more dominant in structuring the individual's capacity and agency to engage in appropriate health-seeking and health-promoting behaviours (see also Barnett 2011). Secondly, while the capacity and importance of such models to identify the individual cognitive factors related to health-related behavioural intentions or behaviours is acknowledged, they offer limited insight into how these cognitive factors may be changed in a reality where individual choice may be

constrained (Campbell, 2003). There however some good examples of psychology-based approaches that place significant emphasis on the social context (see e.g. Rene Brandt's (2007) research amongst PLWH in Cape Town where she compares the impact of both HIV and poverty on individual coping mechanisms of poor HIV-positive women). There are, however, good reasons for the dominance of psychology, public-health and medical knowledge over social and cultural theory, and these disciplines have added greatly to the body of knowledge of HIV/AIDS. As Stuart Hall notes with regards to cultural theory and AIDS:

> "AIDS is one of the questions which urgently brings before us our marginality as critical individuals in making real effects in the world. And yet it has often been represented for us in contradictory ways. Against the urgency of people dying in the streets, what in God's name is the point of cultural studies? What is the point of the study of representations, if there is no response to the question of what you say to someone who wants to know if they should take a drug and if it means they'll die two days later or a few months earlier? At that point, I think anybody who is into cultural studies seriously as an intellectual practice, must feel, on their pulse, its ephemerality, its insubstantiality, how little it registers, how little we've been able to change anything or get anybody to do anything." (1992: 285).

Since Hall's comment in 1992, the global HIV/AIDS landscape has changed dramatically. Antiretroviral therapy has progressed from less than five drugs available at expensive price points (and largely unaffordable in developing countries) in the early nineties to nearly thirty drugs currently (many at highly discounted prices for developing countries) (MSF 2011). Funding to address the epidemic has increased dramatically through multilateral initiatives such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), and President Bush's Emergency Plan for AIDS Relief (PEPFAR).[15] Between 2002 and 2007, global funding for AIDS increased by a factor of four (KFF/UNAIDS 2008). In 2007, international financial assistance for AIDS from the G8, EC, and other donor governments reached its highest level ever with commitments totalling US$ 6.6 billion up from US$ 5.6 billion in 2006. Changes in South Africa have also been dramatic. In 2001, only 1.3% of AIDS-sick individuals had access to HAART, increasing to over 500,000 on HAART through the public sector by December 2008 (UNAIDS 2009: 143), and again increasing to 1.79 million by the middle of 2011 (Johnson 2012). But since the 2008/9 global financial crisis, funding for AIDS has slowed

[15] See http://www.fda.gov/oashi/AIDS/miles.html for a history of AIDS drug development. See Illife 2006 for an excellent history of AIDS in Africa. Also see Whiteside 2008 for brief and concise history of the epidemic.

dramatically, forcing UNAIDS to adopt its new Investment Framework which prioritises doing more with fewer resources and aligning funding with needs to keep the momentum of AIDS response going (UNAIDS 2011:26).[16]

Now more than ever, we need to develop insights from the social sciences and humanities to assist our understanding of why certain responses have had limited success (for example, continued new HIV infections despite HIV prevention efforts and persistent problems of loss to follow-up with regard to HAART programmes) and where we need to sharpen our understanding of the social-psychological context (Barnett 2011). For example, the South African National HIV Prevalence, Incidence, Behaviour and Communication Survey in 2008 reported that 23% of men aged 15-49 who had more than one sexual partner in the past 12 months did not use a condom during last intercourse (and 32% in the case of women). We should be asking why such high percentages of men and women continue to engage in unsafe sex despite the breadth of prevention campaigns. Similarly, Maughan-Brown (2010) reports that stigma amongst young people in the Western Cape has increased despite the roll-out of HAART. We should be asking why the general public continues to have discriminatory perspectives of PLWH despite increased access to prevention and treatment interventions and improved social policies. The list of questions goes on.

LeClerc-Madlala reminds us that "AIDS is more than a simple biomedical entity, it is also a cultural construction …heavily laden with meanings that shift, expand and change as the epidemic grows" (2001: 38). People's perceptions of AIDS are no doubt shaped by a wide variety of factors including: inequality and poverty (Farmer 1999; 2006); the context-laden nature of AIDS stigma in their communities (Deacon *et al*, 2005); their understanding of the source of illness and misfortune (Ashforth, 2005; Stadler 2003) the questioning of conventional science by the South African government (Nattrass 2007, Grebe and Nattrass 2011); the availability of HAART, and their exposure to 'treatment literacy' initiatives by organisations like the TAC (Ashforth and Nattrass, 2006). The decision to disclose one's HIV status to others occurs within this shifting web of meanings – which in turn are reshaped as relationships and social understandings change through the process of individual HIV disclosures.

The following sections outline several theoretical frameworks that contribute useful ideas for improving our understanding of the experience of living with HIV/AIDS in South Africa.

[16] While the UNAIDS Investment Framework advocates for greater efficiency in the global AIDS response, it nevertheless continues to argue for more resources for AIDS to $24 billion by 2015

Firstly, the chapter considers the 'risk society' approach as a broad sociological framework in which to understand the more micro-theoretical frameworks (focussing specifically on disclosure and stigma) that follow. The risk society approach is particularly useful as it locates HIV/AIDS in a global paradigm of rapid change - change that is even more pronounced in developing economies like South Africa. Such change has dramatically influenced perceptions and management of risk, the social relations relied upon by PLWH, as well as the understanding and ownership of expert knowledge. The chapter then moves to an explanation of AIDS-stigma in the general population, a critical contextual factor influencing the life experience of PLWH. The chapter then discusses some of the theoretical frameworks that have direct relevance to experiences of disclosure, for example, 'communication boundary management' (CPM) (Petronio 2002; Greene et al 2003) and the 'stigma trajectory' theory (Alonzo and Reynolds 1995). By drawing on both macro and micro theoretical frameworks, the chapter sketches a broad theoretical framework in which the experience of living with HIV in Khayelitsha can be conceptualised. This is a quintessentially multi-disciplinary endeavour. As Jean Benoist and Alice Desclaux put it:

> "The conditions limiting or promoting (HIV) transmission, illness representations, therapeutic itineraries, and health care practices— none of these subjects are captured by disciplinary approaches. They evade even the distinction between biology and social sciences, so tightly are biological realities tied to behaviors and representations, revealing links that have not yet been fully explored" (Benoist and Desclaux 1995: 363. Translation in Farmer 1999: 33)

3.2 Modern risks and HIV/AIDS in South Africa

There is a large and diverse body of literature on 'risk society', specifically related to health and also related to HIV/AIDS (see for example Beck 1992; Bujra 2000; Caplan 2000; Day 2000; Elbe 2008; Lupton 1995; 1999; Joffe 1999; Schoepf 2004; Turner 1987). Much of this literature builds upon the seminal work of Heinrich Beck, Anthony Giddens and Mary Douglas from which they utilise and expand on relevant concepts.[17] While none of this research is South Africa-based, such diverse theories of risk provide us with a comprehensive set of ideas in

[17] These works include – Ulrich Beck (1992; 1995; 1999), Anthony Giddens (1990; 1991) and Mary Douglas (1969; 1985; 1992). Helene Joffe's work on stigma and her widely used social psychological approach to risk is also an important study that aims to fill the gap between different approaches to risk and their reference to HIV/AIDS (Joffe 1999).

which to understand and explore perceptions of HIV/AIDS and the experience of living with HIV, especially HIV disclosure.

Although Ulrich Beck and Anthony Giddens do not have any particular concern with HIV/AIDS in the developing world, some of their ideas can be utilised to further our understanding of the experience of living with HIV. According to Beck (1985; 1992); and Giddens (1991; 1992), western society has undergone a shift from 'industrial' to 'risk society' as a consequence of capitalist development, urbanization and globalization (Lupton 2006: 12). As a result of this 'modernisation', new forms of risk have emerged that are universal and cross generally established barriers of race, class and space. Beck uses the example of nuclear radiation to describe such a phenomenon, while others have used examples of 'modern' diseases such as AIDS (Bujra 2000; Day 2000) and Bovine Spongiform Encephalopathy (BSE), more commonly known as Mad Cow disease (Caplan 2000) to make similar points. A common feature of these 'modern' risks is that they are uncontrolled and the costs difficult to calculate. These risks cut across space, time and class and have profound physical and social consequences.

Prior to the development of ARVs and the subsequent international effort to expand access to HAART for people in developing countries, AIDS could also be seen in this light. As a survey respondent in rural Tanzania in the late 1990s put it: "People fear AIDS because it is everywhere and has come to stay and because it kills. People fear death, many have died. Not only this village, it's world-wide" (Kapulanga survey respondent in Baylies and Bujra 2000: 60). The HAART era, however, has introduced more of an element of individual control over HIV disease progression, but its ultimately fatal nature still renders the disease terrifying and requiring people to engage with the risks of both acquiring, living with and transmitting the disease to others, notwithstanding the social risk of being identified as HIV-positive in the context of having a socially-stigmatised disease.

Beck (1992: 27) asserts that there are 'distinctive diseases of modernity' in modern society. AIDS is a good example in that its spread in Africa was facilitated and conditioned by urbanisation and trade – both products of capitalist development (Iliffe 2006). The people most at risk and also seen as the vectors of the diseases were migrants, truck drivers and commercial sex workers – all related to economic development and all activities on which people's livelihoods depend. But whether Beck's thesis of the 'risk society' is useful for the African context is moot. It has been critiqued for being historically determined and hence representing

a certain time in contemporary German history and as down-playing the kinds of social inequalities so evident in developing economies (Bujra 2000; Seekings 2008).

Even so, there is nothing inherent in Beck's idea of the risk society that renders it incompatible with its application to other countries – the challenge is simply to use it in appropriately contextualised ways. Furthermore, a focus on risk can draw on additional literatures which are more sociological in nature. For example, Mary Douglas's (1992) social-symbolic approach to risk is based on her work on the cultural meanings associated with concepts of 'purity, pollution and otherness' (in Lupton 2006:13). Individuals conceptualise their notions of their community symbolically, and police inflows and outflows in order to maintain community cohesiveness. Symbolic boundaries are drawn in order to protect the community from outside threats. According to Douglas (1992), risk is a cultural strategy that helps communities make sense of threats and mitigate danger from 'others', an approach adopted by Joffe (1991) to explain HIV-stigma – a phenomenon of central importance to this research. Joffe argues that people may cope with such fears and dangers (e.g. that everybody will eventually die from AIDS) by constructing negative representations of PLWH (the risk or threat), and subjecting them to various forms of exclusion and discrimination in order to distance themselves from the threat. As a consequence, people outside the group (the 'other') suffer from a 'spoilt identity' as theorised by Goffman (1963) if they happen to fit within such representations.

The following section describes some of the appropriate applications of 'risk society' concepts to AIDS in South Africa in general and more specifically the experience of living with HIV and AIDS-stigma.

3.3 Risk and individualization

Elliot (2002) argues that a key component of Beck's risk thesis is the concept of individualisation. Individualisation represents a fundamental change in the relationship between the individual and society (Seekings 2009), where modernisation is not only about risk, but also about expansion of choice as increasing areas of life are disembedded from tradition (Elliot 2002). In the context of Khayelitsha, this process is evident in the declining importance of 'traditional' relationships – notably marriage – but also with regard to the ways in which kinship ties are being reshaped, and in some respects weakened (Russell 2002, Seekings 2008).

The 'Abstain, Be-Faithful and Condomise' (ABC) approach to HIV prevention is a good example of a strategy designed within the context of an 'individualized' society (the USA), implemented in various other socio-economic and cultural situations – possibly with negative implications for PLWH. It is a strategy that promotes individual responsibility for sexual behaviour in a way that is framed in terms of the choice to abstain from sex until marriage, the choice to be faithful to a single partner, or the choice to use condoms. The implication of this is that if infection does occurs, any one or more of these three 'golden rules' must have been broken, and hence that the responsibility for infection is due to the failure of the individual to make the correct choices (Stein 2003: 12). Thus, despite the fact that people may adhere to the 'rules' but still get infected because their partner does not, or that some women may not be able to make real choices around their sexual behaviour (Brandt 2006), the ABC approach frames HIV disease in a way which blames individuals for their own HIV infection. This, in turn, discourages people from disclosing their HIV status, and hence has the effect of increasing the risk of spreading HIV to others. In this way, the manner in which individuals manage the risks associated with HIV disclosure has profound implications for the path of the epidemic.

3.4 Risk, trust and intimate relationships

According to Giddens (1991), trust is no longer based on traditional (and stable) social relationships, but must be earned and negotiated in the context of relationship dynamics which change (sometimes dramatically) over time. Trust in contemporary society is thus to some extent determined by a so-called 'leap of faith'[18] due to the insecurity of traditional social relations in the modern context that previously could be more securely relied upon (Giddens 1991: 244). This is particularly pertinent when considering disclosure of HIV status because if trust has been eroded, sharing one's 'HIV secret' is more difficult when one perceives people to be less trustworthy and the risk of them telling others is high or the likelihood of them providing support is perceived to be low. Janet Bujra argues that the twin concepts of 'risk' and 'trust' are central to the discourse of AIDS in Tanzania.

> …condoms are a device encapsulating safer sex and adopted to reduce risk – particularly in situations where there is no trust. At the same time, I show for Tanzania, condoms are themselves seen as risky and dangerous, whilst their use, rather than

[18] The usage of the word 'faith' in this case and throughout the thesis is in the non-religious sense

> inducing trust in partners, actually symbolises and augments distrust. The form in which trust is invested is socially constructed; the risk of AIDS disrupts the investiture and puts time-honoured social relations in question: to trust is now to court risk. If trust is so basic to human security and to 'inner authenticity' as Giddens argues (1991: 215), then how can people rebuild trust whilst at the same time fighting against the risk of AIDS? (Bujra 2000: 60)

The concepts of 'risk' and 'trust' are also central to the discourse of AIDS in South Africa, and can be extended to the disclosure needs and constraints of PLWH. The HIV-disclosure process is dominated by issues of trust regardless of who the recipient may be – but especially so with regard to sexual relationships. As will be shown in Chapter 8, trust in sexual partners from the women's perspective is low in Khayelitsha. Trust is therefore more like a 'leap of faith' especially when disclosing ones very private HIV-status to men, in whom very little trust exists due to both dynamics of relationships, perceptions of men's persistent infidelity, and past negative relationship experiences, both with intimate partners and male biological household members. Women are therefore at a double disadvantage – they neither trust men to keep a secret or to give them support, nor do they trust society to react positively to their disclosure of their stigmatised HIV status. Chapter 8 sheds more light on the dynamics of disclosure in sexual relationships, whereas instead of disclosure being the means to access much need psycho-social support and to build trust in relationships (especially in sexual relationships), disclosure symbolises and augments risk, while simultaneously encouraging further distrust (see also Mills and Maughan-Brown 2009).

Mark Hunter's (2006) research in Kwazulu-Natal (KZN) sheds light on trust and relationships in contemporary South Africa. Hunter uses historical ethnography to argue that intimate relationships have changed over time – largely as a consequence of the collapse of the migrant labour system, rising rates of unemployment and increasing numbers of women migrating to cities. Informal settlements have grown dramatically (e.g. Khayelitsha), especially in the post-apartheid period, in conjunction with declining marriage rates, more informal relationships and more women-headed households. 'Traditional' social relations with kin, in particular patrilineal kin, are no longer guaranteed due to the high levels of flux in household dynamics (Seekings 2009). The social relations on which sick people rely and in which high levels of trust exist can no longer be taken for granted. This is particularly important for people wanting to disclose their HIV-status to household members in order to gain support or access treatment and care in a context of heightened risk and reduced trust.

3.5 Changing ownership of expert-knowledge

A key tenant of risk society is that it is a product of the changing nature of science and scientific hegemony (Beck 1999). This includes the symbolic 'opening up' of science and a challenge to scientific hegemony through the continual uncertainty about what advice or information to trust (Flynn 2006). In both advanced countries and the developing world, people have increasing access to information through increased access to education, and through mediums such as the internet. On a micro scale, HIV/AIDS is a good example of this change. As will be described in Chapter 8, a primary motivation provided by women in the qualitative study for disclosing their HIV status to their sexual partners was to avoid re-infection[19] with different strains of the HIV virus. In this respect, the respondents embraced the scientific explanation and took concrete steps to protect themselves within the frame of that understanding. The ability of lay people to engage with complex virology and its potential impact on their health is certainly an interesting and important phenomenon and demonstrates the high levels of scientific knowledge accumulated, owned and interpreted by lay people in South Africa, especially PLWH (see also Ashforth and Nattrass 2006). As Sipho Mthathi writes in the Treatment Action Campaign *Equal Treatment* newsletter:

> With treatment literacy[20], it becomes possible for people to draw conclusions about HIV for themselves and not because they are being told by a priest or doctor, for example that condoms used regularly can prevent HIV infection or that proper eating and taking your medicines correctly will ensure that you live a longer and healthier life. Treatment literacy empowers PLWH and those who support them … We believe that ordinary people can learn the science of diseases and medicine. People who are treatment literate

[19] Reinfection, also known as superinfection 'is defined as infection by a second strain of HIV after initial infection by a primary strain has been established. The clinical consequences of superinfection for an individual vary, but may include accelerated disease progression and the acquisition of drug resistance. The public health consequences of HIV superinfections are unclear. While superinfection can result in recombination between genetically different viruses, and a number of circulating recombinant forms are prevalent in certain geographic areas, it has not been demonstrated that such recombination results in the establishment of more transmissible or virulent viruses. There is also evidence that superinfection occurs only rarely in HIV-infected individuals on effective ART.' http://www.thebody.com/content/treat/art53776.html accessed 04/05/2005

[20] 'Treatment literacy' is the term describing TAC's HIV/AIDS and antiretroviral education campaign. This campaign aims to educate lay people about the science of HIV/AIDS, disease and HAART. The TAC newsletter, Equal Treatment, describes a situation where patients, regardless of formal education, are able to ask their doctors: "Why are you prescribing this medicine? What are its side effects? Are there generic alternatives? Why am I not being given this medicine instead? What diagnostic tests should I take and how often?" (TAC 2007: 5)

> take medicines because they understand the evidence that shows they work, not just because they have been told it works. (TAC 2007: 5)

Similarly, the large numbers of internet websites and publications describing complex virology, physiology and immunology to lay people has made scientific knowledge more accessible, especially in urban contexts such as Khayelitsha.[21] However, as a consequence of this shared knowledge, people may feel both empowered to contribute *and* challenge scientific hegemony leading to a consequent increase in what Nathan Geffen and others term 'scientific quackery' (Geffen 2011). Notably, South African president Thabo Mbeki took it upon himself to engage with aspects of the science of HIV, arguing that it was 'absurd' to abrogate health policy to the scientists (see Nattrass 2007: 70). In her paper on adherence to HAART, Elizabeth Mills found that patients on HAART were thus 'swimming in confusion' due to the multiple sources and layers of information on HIV/AIDS in the public domain (Mills 2008: 6). However, the 'decentralisation' of scientific knowledge has also proven important in the ways PLWH manage their disease. In the Khayelitsha context, it has been argued that HAART patients have a detailed understanding of the medical dimensions of their treatment and that this is a major factor behind the success (in terms of good adherence) of the HAART program (Hodes and Holm Naimak 2011). According to Grebe and Nattrass (2011), whether people trust HIV science is linked both to their exposure to the TAC and to their trust in Mbeki's health minister. This, in turn, speaks to the fluid and contested terrain of HIV beliefs.

3.6 HIV/AIDS-related stigma or AIDS-stigma

Broadly speaking, stigma may have a serious impact on the incidence, experience and management of medical conditions, especially HIV/AIDS, due to the need to avoid potential risks resulting from being identified as having the stigmatised condition thus limiting important support-seeking behaviours. Stigma, as a phenomenon, has also been investigated in a diversity of medical conditions such as leprosy (e.g. Heijnders 2004), sexually transmitted infections (e.g. Lichtenstein 2003), lung cancer (e.g. Chapple et al 2004) and tuberculosis (e.g. Rajeswari et al 2005), as well as HIV/AIDS (see Deacon et al 2005 for an excellent review of the stigma literature). However, stigma seems to be linked especially to diseases that are fatal, communicable and sexually transmitted (Crawford et al 2006). This is the case with HIV – a disease characterised by multiple and layered negative attributes.

[21] see for example: www.thebody.com; www.tac.org.za and TAC's magazine *Equal Treatment*

Early work in the pre-HAART era argued that stigma exacerbates the physiological effect of HIV/AIDS on individuals, a bi-directional effect between the social and physical condition (Holt et al 1994; McGrath 1992). It continues to have a negative impact in the AIDS treatment era. In the South African literature, stigma is most often identified as the primary reason for reluctance by PLWH to disclose their HIV-positive status (Brandt, 2007; Maughan-Brown 2008; Skhosana et al 2006; Kalichman and Simbayi 2003), or for members of the general population not to access important health services such as VCT (Van Dyk and Van Dyk 2003; Hutchinson and Mahlalela 2006). Both South African and international studies have also identified stigma as a reason for poor coping strategies including: not accessing care (Sayles et al 2007) and a significant cause of non-adherence to HAART (Chandra, Deepthivarma & Manjula 2003; Kilewo et al 2001; Klitzman et al 2004). Stigma has also been used to explain negative attitudes and discrimination against PLWH in the family, at work, in the community and in healthcare environments (Bollinger 2002; Malcolm et al 1998; POLICY Project 2003; Richter 2001).

The international literature on AIDS-stigma is extensive, largely as a result of the widespread acknowledgement in clinical and policy-making circles of the potential impact of the stigma on preventative behaviour, care seeking behaviour, and quality of life for PLWH. As Parker and Aggleton noted: "Internationally, there has been a recent resurgence of interest in HIV and AIDS-related stigma and discrimination, triggered at least in part by growing recognition that negative social responses to the epidemic remain pervasive even in seriously affected communities" (2003:13).

The interest in stigma and discrimination towards PLWH was also in part triggered by the efforts and policy recommendations of the Joint United Nations Programme on HIV/AIDS (UNAIDS), the leading international HIV/AIDS body, specifically through the numerous public speeches of Peter Piot, its former Director. For example, at the 2001 International Conference on Racism in Durban, South Africa, Piot noted "HIV-related stigma and discrimination remain an immense barrier to effectively fighting the most devastating epidemic humanity has ever known. If HIV-related stigma and discrimination are not tackled, AIDS will blight the 21st century just as racism affected the 20th century." The 2002-3 World AIDS Campaign was a major push to place stigma and discrimination on the global AIDS agenda with the slogan *Live and Let Live* that focussed on eliminating stigma and discrimination towards HIV/AIDS as the major obstacles to comprehensive prevention and care (UNAIDS:

2002). Other large international development organisations have also targeted stigma and discrimination in their anti-AIDS campaigns. In 2002, the Red Cross/Red Crescent launched '*The truth about AIDS. Pass it on...*', a campaign to reduce HIV/AIDS-related stigma and discrimination, to educate people about HIV/AIDS and warn against the dangers of stigmatising those who are infected, or their families. The International Council of Nurses campaign theme for 2003 was '*Fighting AIDS stigma: Caring for all*'. The centrality of stigma and discrimination continues to remain at the heart of the global HIV/AIDS response as defined in the UNAIDS Strategy for 2011-2015 entitled 'Getting to Zero' with the tagline: 'zero new HIV infections; **zero discrimination**; zero AIDS-related deaths' (UNAIDS 2010).

However, the persistent focus on the negative aspects of AIDS-stigma may in some cases have had the opposite effect from what was intended. Through the constant contextualisation of all things HIV/AIDS-related in terms of AIDS-stigma (except for in the biological and/or clinical sciences), researchers may inadvertently be reinforcing and reproducing the dominant causal mode of thinking, that is - HIV/AIDS is a stigmatised disease, PLWH are therefore discriminated against and the social life of PLWH is therefore under constant stress and threat, resulting in very low levels of disclosure and agency. Seldom do we hear about the more positive experiences of living with HIV (for example, obtaining unexpected support, forging new and better relationships) or the ways in which society (on both micro and macro-levels) is changing and adapting to the AIDS epidemic in sub-Saharan Africa. We have little appreciation of the dynamic context within which PLWH negotiate their relationships with others, including disclosing their HIV status to a variety of people, on numerous occasions and over a long period of time. As noted earlier, this study attempts to fill this gap by means of a mixed methods study of the dynamics of disclosure in Khayelitsha.

3.7 What are PLWH up against? Theoretical underpinnings of AIDS-stigma

Discussions of AIDS-stigma typically use Goffman's (1963) seminal work on stigma as the point of departure (e.g. Maughan Brown 2008; Parker and Aggleton 2003; Simbayi et al 2007; Stein 2003). Such research is similar in terms of theorisation and interpretation of the stigmatised individual as an individual possessing 'an attribute that is deeply discrediting' (Goffman, 1963: 13). Social science literature that has conceptualised stigma or AIDS more broadly in this way has been critiqued for its lack of appreciation of the social and economic context shaping the stigmatising environment (Farmer 1999; Stein 2003). This concern with the

stigmatised and discredited individual is historically embedded within the context of US and European-based research where the bulk of infections were in already-stigmatised risk groups such as men who have sex with men (MSM), injecting drug users (IDUs) and commercial sex workers (CSWs) (Karon et al 2001). Concern with the individual thus dialogued also with a rights-based advocacy approach which sought to protect individuals and to assist them in overcoming both social stigma and internal stigma (i.e. where stigmatising social attitudes are internalised psychologically by the person being stigmatised). But this psychology-based approach is limited in its ability to provide a comprehensive understanding of some the crucial underlying questions such as: What is the social context within which stigmatisation takes place? How do PLWH's responses reshape or reinforce societal norms?

Citing Goffman in support of an interpretation of stigma as an individual attribute potentially misunderstands the sociological depth of his concept. Goffman's full quotation reads as follows: "*The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is needed*" (Goffman, 1963: 13). Goffman's interpretation of stigma is therefore founded within a broad sociological perspective, in particular, a symbolic interactionist perspective. The 'attribute' is a contested concept shaped by relationships between the individual and his or her world, in particular the expectations defined by and within different relationships. Alonzo and Reynolds argue, "a given attribute that is stigmatized is not inherently pathological, immoral, or 'deviant', but derives from culturally imbedded meanings. Thus, various forms of 'deviance' are stigmatized in the context of a particular historic period and cultural context" (1995: 304). For example, MSM were stigmatised in the 1980s when the disease was first discovered among five homosexual men and largely concentrated within the homosexual community in the USA (Herek 1991).

In terms of defining and breaking down the various AIDS-stigma concepts, it is important to acknowledge two critical factors: that HIV/AIDS is a life-threatening and transmissible condition; and that HIV is associated with bad and/or deviant behaviour, or those groups practicing such behaviours.

Fear of contagion – Instrumental Stigma

HIV is an incurable and life-threatening communicable disease. The degree to which it is life threatening is of course mediated by access and adherence to HAART (Siegfried, Uthman & Rutherford 2010). HIV is transmitted sexually (in sexual fluids) and through blood-

contaminated body fluids. The extent to which it is communicable is variable and is determined by the amount of virus in the infected person's body (Attia, Egger, Muller, Zwahlen and Low 2009), the presence of sexually transmitted infections (Ward and Ronn 2010), and the particular sex act (Dosekun and Fox 2010). Stigma which has its origin in fear of the infectiousness and the terminal nature of HIV has been labelled 'instrumental' stigma by social scientists such as Herek and Capitanio (1998) because it encourages behaviour (such as refusing any contact with HIV positive people) that is believed to decrease risk of infection. They argue for a distinction between instrumental stigma, which arises from utilitarian self-interest, and symbolic stigma, which arises from a value-based ideology (i.e. moral indignation at the behaviours seen as resulting in AIDS – such as sexual promiscuity).

A commonly reported example of instrumental stigma is fear of using cutlery and crockery previously used by an HIV-positive person or shaking hands with an infected person. In his research amongst young adults in Cape Town, Maughan-Brown (2008) asked the question: 'If you knew a shopkeeper had HIV/AIDS, would you still buy fresh vegetables from him or her?' in order to determine respondent's 'behavioural intentions' towards PLWH. He found that 11% of respondents reported that that they would definitely not purchase vegetables under such conditions (ibid: 89). In their cross-country research on AIDS-stigma in three African countries, Nyblade et al (2003) found that instrumental stigma was indeed related to stigmatising behaviours such as avoiding PLWH:

> "There are neighbours who visit the patient and there are those who don't visit the patient. The neighbours who visit the patient know that AIDS is not transmitted through breath, but they know that it gets transmitted through using some materials [needle and razor]. On the other hand, neighbours who don't visit the patient believe AIDS is transmitted through breathing or eating together. (Rural man, Ethiopia cited in Nyblade et al 2003: 17)

Instrumental stigma as described above is most often mitigated through education campaigns educating people on the scientific facts of HIV-transmission such as 'HIV can only be transmitted through the exchange of body fluids', and 'you cannot be infected with HIV through sharing a toilet seat'. Instrumental stigma may well decline in relation to increased access to HAART as HIV is rendered a chronic and manageable, rather than a terminal, disease (Orr & Patient, 2003; Nattrass, 2003). However, research amongst the general population in the Western Cape revealed that stigma actually increased in between 2004 and 2006 – i.e. during

the period of the HAART rollout (Maughan-Brown 2010). As ever, simplistic conclusions based on hoped-for correlations should be avoided.

Value-based judgements – Symbolic Stigma

Symbolic stigma is differs from instrumental stigma in that it is a function of value judgements or value-based ideologies rather than fear of infection per se (Deacon et al 2005; Herek and Capitanio 1998). The origins of symbolic stigma are complex and draw from the history of HIV/AIDS in specific contexts as well as socially constructed associations with already-stigmatised groups or behaviours. In the industrialised world, HIV has been perceived as a virus that affects largely MSM, commercial sex workers and IDUs, all behaviours that are already considered deviant by many. Symbolic stigma occurs when HIV-positive people (fairly or unfairly) are linked with such behaviours and hence judged as deviant (Herek and Capitanio 1998). PLWH are considered responsible for acquiring the virus, which is inferred to be a result of irresponsible and/or deviant behaviour. The layering of stigma on certain individuals or groups has also been termed 'double stigma' or 'compounded stigma' (Kowalewski 1988) where for example, MSM are already stigmatised for their sexuality and also stigmatised for being HIV-positive. In the South African context, Adam Ashforth found that in Soweto, HIV/AIDS was associated with being bewitched thus resulting in PLWH being both stigmatised for being HIV-positive and for being cursed and therefore impure (Ashforth 2005). Further research in South Africa through quantitative methods amongst the Xhosa in South Africa has provided additional evidence of the perceived association between witchcraft and HIV/AIDS (Kalichman and Simbayi 2004; Steinberg 2007).

Symbolic stigma is said to serve a protective psychological function through creating a symbolic and protective barrier between 'us' and 'them', a psychosocial process also known as 'othering' and a mechanism to reduce the perceived risk posed by the 'other' group (Joffe 1999). This protects the stigmatising individuals from fear and anxiety related to both their own behaviour and that of others. With regards to stigmatising individuals' own behaviour, the protection gives them confidence that their behaviour (and that of people like them) is acceptable and is not putting themselves at any physical risk. The stigmatisation of minorities and disliked groups more broadly, as has been a major theme throughout the history of the AIDS epidemic, is evidence of an 'us versus them' mindset adopted by the general population (Castro and Farmer 2005; Gilmore and Somerville 1994; Joffe 1999). In some way, symbolic stigma may also be understood as instrumental stigma as it too serves a utilitarian function of

protecting oneself and one's community from the potential threat posed by outsiders (Stein 2003).

3.8 Understanding how PLWH manage the risks posed by AIDS-stigma in the context of a bio-psychosocial experience of HIV disease

In order to understand PLWH's experiences of disclosure, we need to understand how stigma in the general population is processed at the level of the individual. Greene et al. (2003) argue that fear of stigma and the associated risks contribute to HIV-positive people setting up defensive 'boundaries' around their private information. Petronio (2002) and Greene et al. (2003) have developed a conceptual framework for analysing HIV-status disclosure based on so-called 'communication privacy management theory' (CPM). The CPM framework links well with relevant concepts from the risk approach as it attempts to frame the ways in which the social context, specifically risk of negative outcomes of disclosure, is processed at the individual level. CPM postulates that individuals develop rules for managing their privacy boundaries in order to minimise the risks associated with disclosure. In other words, CPM theory provides a map of how people control private information. There are five core principles of CPM (Petronio 2002 in Griffin 2012:168-169):

1. People believe they own and have a right to control their private information
2. People control their private information through the use of personal privacy rules
3. When others are told or given access to a person's private information, they become co-owners of that information
4. Co-owners of private information need to negotiate mutually agreeable privacy rules about telling others
5. When co-owners of private information do not effectively negotiate and follow mutually held privacy rules, boundary turbulence is the likely result.

The privacy rules and boundaries set up by the individual exist within, and are influenced by, five general criteria: cultural, gendered, motivational, contextual, and risk-benefit criteria. These criteria provide the context in which the disclosure process occurs.

When private information is disclosed to a trusted individual, he or she enters the 'privacy boundary' of the person disclosing the 'secret', and is required to subscribe to the rules of the person disclosing. If the trusted person tells other people and breaks the trust, the person who

initially disclosed the private information will experience 'boundary turbulence'. Similarly, boundary turbulence may be caused by a loss of control over one's HIV secret when large numbers of people are disclosed to (as in the case of public disclosure) leading to a significant loss of control over how the 'secret' is managed. (Obviously, public disclosure seems to imply consent that one's HIV status no longer has to be managed like a secret) The concept of 'boundary turbulence' is particularly relevant to the current research due to high levels of fear of being identified as HIV-positive. CPM provides a useful organisational principle for many of the issues surrounding the disclosure process, but needs to be employed in a way that takes cognizance of the changing political and economic response to the epidemic, the changing socio-cultural norms over time, and the ability of individuals to cope with a 'dynamic disease'.

One of the important contextual factors shaping HIV disclosure is the 'biophysical trajectory' associated with HIV disease (Alonzo and Reynolds 1995). PLWH experience several clinical stages of HIV disease (as defined by the World Health Organisation). Exact progression times vary across individuals and are strongly influenced by socio-economic context (Gallo et al., 2006). After infection (and sero-conversion), the person may be asymptomatic for a number of years (see Table 3.1 below). As the immune system becomes increasingly compromised by HIV infection, the individual experiences more and more opportunistic infections, is less able to hide his or her disease from others, and is more in need of care and support. However, as access to HAART, PMTCT, VCT and other health services increase, fewer people will experience AIDS-defining illnesses as people will start treatment earlier (Boulle et al 2010). And, as the biophysical trajectory plays out, both in relation to the individual's mental health and to access to treatment and support services, the individual's social relationships may change.

Alonzo and Reynolds (1995) usefully conceptualised living with HIV as a bio-psychosocial experience, a dynamic movement between a biophysical disease trajectory and a 'psychosocial stigma trajectory'. Writing in the pre-HAART era, they argued that we need to 'conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are affected by changes in the biophysical dimensions of HIV/AIDS' (ibid.303). The changing experience of stigma is categorised in four phases: '(1) at risk: pre-stigma and the worried well; (2) diagnosis: confronting an altered identity; (3) latent: living between illness and health; and (4) manifest: passage to social and physical death' (Alonzo and Reynolds 1995: 303). Unlike the disease trajectory, the accompanying social trajectories are fluid, context specific, and are the product of dynamic interaction between the individual and his or her social sphere. As will

be illustrated in this thesis, the social context affects the decision to disclose, but can, in turn, be reconstituted by it.

There have been other models of disclosure tested by various researchers, mostly in the US. Serovich (2001) for example, compared two disclosure theories that focus on the impact of disease progression on the decision to disclose: the disease progression theory; and the competing consequences theory. The disease progression theory provides a model of disclosure whereby the HIV-positive person discloses his or her HIV status when HIV progresses to AIDS, thereby making it impossible to keep his or her status a secret any longer (Babcock, 1998 & Kalichman, 1995 cited in Serovich 2001). The progression of HIV leads to a severely compromised health status characterised by visible signs of illness and hospitalisation. The competing consequence model assumes that there is no direct linear relationship between disease progression and disclosure (Serovich 2001: 5). When sick, the person first weighs up the risks and benefits of disclosure (assesses the consequences) and then discloses accordingly.

The disease progression theory is arguably over-simplistic in the way it assumes very little volition on the part of the HIV-positive person. This theory assumes a direct and causal relationship between health and disclosure, whereby a person will necessarily be forced to disclose in order to gain necessary support or resources. There is little room for the person to decide to disclose before becoming sick with AIDS, and there is limited conceptual space for exploring the decisions of people made healthy by HAART and those experiencing the changing dynamics of long-term HAART (some of which also entails adverse and visible health consequences). The competing consequences model is more flexible as it gives more agency to PLWH and can accommodate a wider range of disclosure experiences. In testing the two theories amongst 138 HIV-positive MSM, Serovich (2001) found that neither theory provided an adequate global understanding of disclosure. More specifically, she found that such theories may explain disclosure to family or friends, but not to sexual partners (a similar finding to this research). Furthermore, neither theory takes explicit account of the way that social context influences disclosure decisions, or for more altruistic motivations for disclosure such as PLWH wanting to educate friends and family about HIV. As will be shown in this study, disclosure is both a response to, and in turn shapes, the social world of PLWH.

Table 3.1: Summary of WHO Clinical Staging System for HIV Management

Stages	*Description*	*Time*	*Physical experiences/symptoms*
Stage 1	Initial infection	0 – 4 weeks	The patient has no symptoms, appears well.
	Seroconversion	Four to sixteen weeks after infection	Many patients have no symptoms. 50% - 80% of patients have a 'flu-like' illness lasting 1-2 weeks. In these patients, symptoms include swollen lymph glands (nodes), high temperature, headaches, sore throat and fatigue.
	Asymptomatic phase	More than 16 weeks after infection	The patient has no symptoms and appears well. Persistent lymph node inflammation may occur due to the high numbers of new lymphocytes being made in the lymph nodes. This stage of the disease may continue for many years**.**
Stage 2	Mildly Symptomatic	Average period of more than four years	The patient experiences symptoms such as: slight weight loss, fatigue, mouth ulcers, skin rashes and itching. Diseases include shingles and recurrent infections of the upper respiratory tract (mouth, sinuses, and throat). These symptoms and infections are categorised as minor and are not life-threatening. However, they may be unpleasant and debilitating.
Stage 3	Symptomatic	Average period of five years	The patient is weaker and spends more time in bed. Symptoms such as high temperature, night sweats and diarrhoea that last for more than a month. Weight loss increases. The patient may have serious infections such as tuberculosis (TB) and pneumonia. Fungal infections of the mouth and genitalia are common (thrush).
Stage 4 – AIDS-sick	Advanced Disease	Average period of 5-13 months	This is the final stage of HIV infection when the patient is said to have developed Acquired Immune Deficiency Syndrome (AIDS). 'Syndrome' refers to the collection of symptoms and diseases that characterise advanced HIV infection. By this stage the patient is very unwell, unable to care for his/herself and often bedridden for long periods. Weight loss is profound. The patient will have one or more serious infections or cancers that cause damage to the organs of the body and are potentially life-threatening.
OR			
Stage 5 (ASSA 2003)	HAART is initiated when a CD4 is <350 cells/mm³	Survival depends on CD4 and age at baseline	

Source: WHO 2005 accessed from www.who.int/hiv/pub/guidelines/clinicalstaging.pdf

3.9 Concluding comments

To the best of my knowledge there is no unified theory to analyse and understand the bio-psychosocial experience of living with HIV, and disclosing one's HIV status in particular. However there are some promising concepts which can be borrowed from different approaches and applied in specific empirical contexts with respect to understanding the dynamics of disclosure. These include different types of stigma (and implications for disclosure strategies), and the way in which this could dialogue with bio-physical trajectories, the way people manage their privacy boundaries in terms of CPM, and the role of risk and trust, both real and perceived. By drawing from these diverse literatures, it is possible to construct a dynamic multi-disciplinary framework to further our understanding of why people make disclosure decisions in the way they do.

As discussed at the beginning of this chapter, the AIDS epidemic was for many years defined by policy-makers, researchers and practitioners in largely bio-medical terms. However, at the same time, the disease had a multitude of meanings for other people, those experiencing the disease for themselves through being infected or through knowing somebody who was infected, and those judging others who may be infected. Treichler (2004) has called this an "epidemic of signification" where the AIDS epidemic has "produced a parallel epidemic of meanings, definitions, and attributions" (ibid.:315).

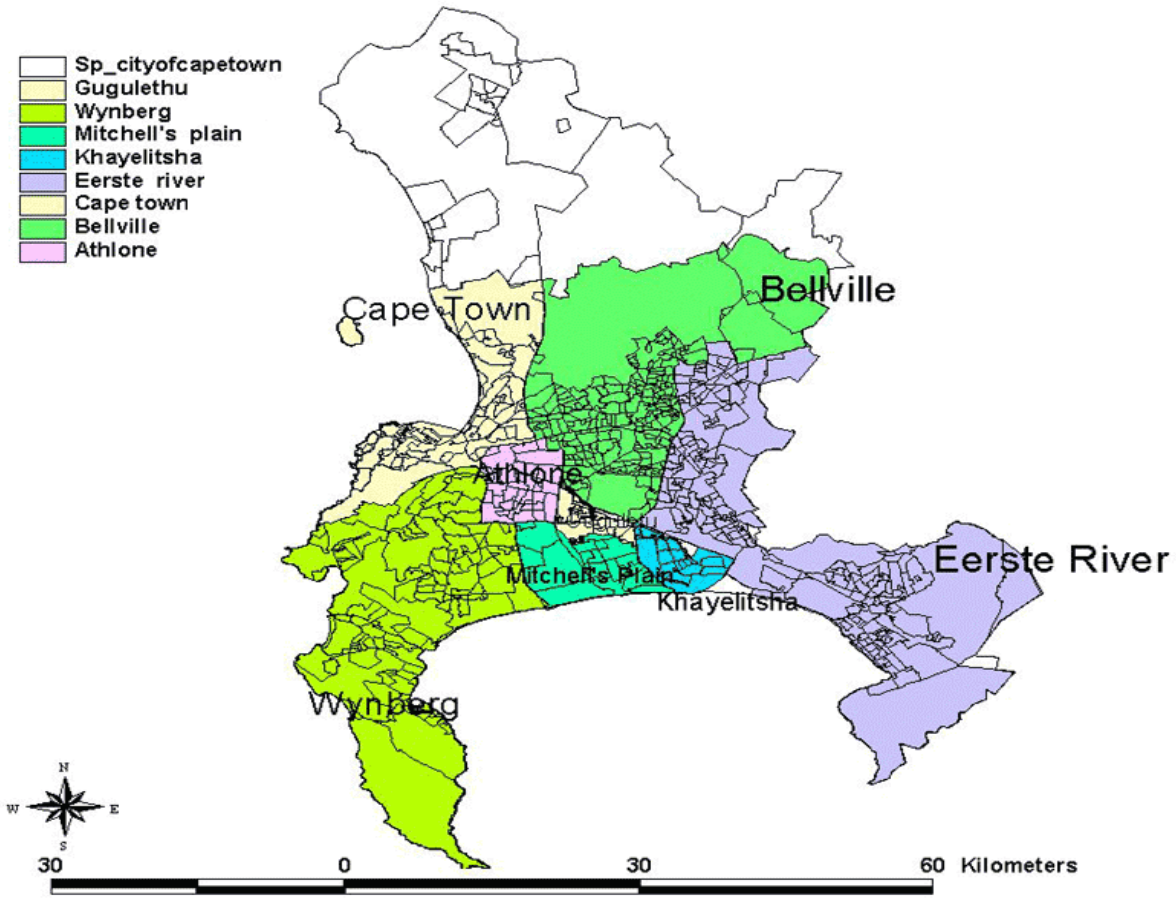
The theoretical concepts reviewed in this chapter suggest that there are psychological, physical and social processes at play in shaping the multiple meanings of HIV disease. But many of these insights were developed in the pre HAART era. Theorising HIV then was simpler in that HIV progressed inexorably towards death with no hope of effective treatment extending life. But, as this chapter has tried to argue, contemporary society is dynamic and allows for complex scientific issues to be understood and interpreted by a much wider range of people than previously. The chapter has also tried to show how elements of the risk society thesis have some merit in understanding HIV within South African society today – specifically how PLWH make difficult life decisions in a social context in flux. In a microcosm of South African society, as in Khayelitsha, this presents many problems as people try to make sense of their lives in a rapidly changing environment, characterised by high unemployment, increasing empowerment of women, decreasing rates of stable partnerships, and increasing access to knowledge and technology. As shown later on in the dissertation, for PLWH, these dynamics are layered upon the physical and psychological experience.

Chapter 4: Study methods and data description

4.1. Geographical location of the study: Khayelitsha, Cape Town, South Africa

An important aspect of any social scientific study is the geographical context of the study. Respondents in both the qualitative and quantitative arms of the study are residents of Khayelitsha, and the majority of the fieldwork took place in Khayelitsha. Khayelitsha is an interesting setting in terms of both the history of South Africa (in that it originated as an apartheid-based group area for Africans in the early 1989s) as well as the response to the AIDS epidemic (as noted earlier, it was the site of the first public sector HAART rollout and is the base of much of the work conducted by TAC). This context inevitably shapes the experience of living with HIV/AIDS in the area.

Figure 4.1: Map of Cape Town, including Khayelitsha (shaded in blue)



Khayelitsha is located in the Western Cape Province – which is not only the richest of South Africa's provinces, but also the most unequal city in South Africa (McDonald 2008: 42). The

Western Cape has also been fiercely politically contested since the end of Apartheid. This is reflected in the province's leadership and governance, the approach to and availability of public health services and, most importantly for this study, it was the first province to introduce a HAART programme (the Khayelitsha programme) – which was done in collaboration with MSF. Table 4.1 illustrates some key socio-economic and health-related differences between the provinces as of 2004/5. Notably, the Western Cape had the highest per capita income, the lowest HIV prevalence, the highest number of doctors per uninsured person, the highest per capita health spending, and the highest HAART coverage. In short, not only did the Western Cape have more political space than other provinces to oppose Mbeki and his health minister's AIDS policies, but it had the resources to do so as well.

Table 4.1: Health, Socio-economic and HAART indicators by Province (Adults) in 2004/5

Prov.	**Start of the Rollout**	**HIV prevalence (2005) – ASSA2003 (%)**	**Share of the total population (%)**	**Doctors per 100 000 uninsured persons (2005)**	**Nurses per 100 000 uninsured persons (2005)**	**GDP per capita (2003)**	**Per capita govt health spending*** **	**Total HAART coverage (%) (end of 2005)***
EC**	May 2004	9.5	14.2	17	108	R12 185	R873	21.8
FS	May 2004	13.7	6.0	32	143	R21 437	R1 193	21.0
GT	April 2004	14.3	20.1	42	105	R36 913	R1 179	29.6
KZN	April 2004	15.6	20.7	27	107	R18 528	R1 017	20.0
LP	Aug 2004	6.7	12.0	14	111	R12 040	R829	27.3
MP	Aug 2004	13.3	7.0	19	93	R20 499	R774	20.9
NC	July 2004	6.5	1.9	38	141	R24 922	R1 238	32.3
NW	June 2004	12.5	8.0	13	90	R17 198	R767	24.5
WC	**May 2001**	**5.0**	**10.3**	**55**	**106**	**R30 628**	**R1 433**	**55.7**
SA		11.0	100	28	109	R22 569	R1 014	25.2

Sources: ASSA 2003; ALP 2006, Nattrass 2006

* The numbers of people on HAART in the public and private sectors as a percentage of the number of people estimated to need HAART (from ASSA2003 demographic model).

** EC = Eastern Cape; FS = Free State; GT = Gauteng; KZN = Kwazulu-Natal; LP = Limpopo; MP = Mpumalanga; NC = Northern Cape; NW = North West Province; WC = Western Cape; SA = South Africa

*** ZAR per uninsured person 2004/5

Cape Town, in which Khayelitsha is a municipality, is South Africa's third largest city. As of 2001, the city had a population of approximately 3.4 million (Census 2001) accounting for about 67% of the Western Cape Province's population (4.6 million). The political administration in the Western Cape has swayed between the ANC, the ANC-NNP[22] alliance

[22] New National Party

and the Democratic Alliance administrations[23]. As a result of this political instability, the Western Cape has often benefited from AIDS policy that was significantly more forward thinking than other provinces that were led by the national policy of the ANC (see Nattrass 2007: 50-51).

Cape Town's demographic make-up is also distinctive amongst other South African cities in that the largest population group is Coloured (46%) followed by Black African (35%) and White (18%) (City of Cape Town 2005). More than most other South African cities, Cape Town bears the scars of the Apartheid's racist policies specifically the Group Areas Act (Act 41 of 1950). Most areas in the Cape Town Metropole are separated along racial lines, and in many cases racial lines also represent class differences. For example, Whites dominate the wealthier areas along the South Peninsula (Cape Town and Wynberg in Figure 4.1) while African and Coloured dominate the informal settlements and low-cost housing on the Cape Flats (Athlone, Mitchell's Plane and Khayelitsha in Figure 4.1).

4.2 A brief history of Khayelitsha – the location of the research

Khayelitsha originated as a response to the severe housing shortage for African migrants coming from largely the former homeland of the Transkei (Eastern Cape today) in the late 1970's and early 1980's (Seekings, Graaf & Joubert 1990). The development of Khayelitsha was announced in 1983 by Piet Koornhof, then Minister of Cooperation and Development. The government's plan was to move all black people considered legally resident in the Western Cape from the existing townships in the Western Cape (such as Nyanga, Old Crossroads and Gugulethu) to Khayelitsha, and the government made provisions to settle 360,000 people there. By 1988, the total population was over 150,000, living in various 'sites' within the broader Khayelitsha. These sites or areas within Khayelitsha arose as the availability of and need for housing grew over time (for example, Site B is older than Site C). Khayelitsha has continued to grow into one of South Africa's biggest townships with an estimated population of around 400,000 people (the 2001 Census estimated a population of 329,002 people and the WC Population Unit Spatial Enumeration 2005 estimates the population at 406,779).

[23] The current leadership of the Western Cape is the Democratic Alliance (DA).

Figure 4.2 An example of the majority of shacks in Khayelitsha

Figure 4.3 A middle-class suburb within Khayelitsha

Figure 4.4 New housing being built as part of the government's reconstruction and development programme (RDP) within Khayelitsha

Khayelitsha's population initially comprised a wide range of people including migrants from the Eastern Cape Province, second and third generation migrants born in Cape Town (who moved to Khayelitsha from the crowded older residential areas of Langa, Nyanga and Gugulethu (Lingelethu West City Council, 1992), and migrants from countries outside South Africa (Seekings, Graaf and Joubert 1990; Statistics SA 2003). Strong traditional elements of community life are still evident and are manifested in the numerous social support systems that exist in the community (Spiegel and Melhwana 1997).

Census 2001 data indicate a population of approximately 327,000, the majority of which (67%) was below the age of 30 and almost all are Xhosa speakers. The unemployment rate was approximately 35% compared to 17.1% in the Western Cape (Census 2001). On average, earnings were low where 25% of the population did not earn an income, and 47% earned less than R20,000 per year compared with 28.8% in the total population of the Western Cape (see Table 4.2). The majority of households in the township lived in an informal dwelling. Most (94%) of children of compulsory school going age (i.e. aged between seven and fifteen) were enrolled in school. Most adolescents aged between fifteen and eighteen were also in school (79%). Among young adults between fifteen and twenty-four, only 22% had a grade 12 or tertiary qualification. According to the Western Cape Socio-Economic review (2003:12), the labour market experience of Africans in the Western Cape was worse than that of Coloured, Asian and White workers in terms of unemployment rates and average wages.

Table 4.2 Khayelitsha's population and income distribution in comparative context[24]

	Khayelitsha	*Cape Town (All Africans)*	*Cape Town (Coloureds)*	*Cape Town (Whites)*	*Cape Town (Total population)*
Population	327,355	916,540	1,392,673	542,554	2,893,244
Annual household income					
No income	25.0%	27.8%	7.2%	4.3%	13.1%
R1-R4,800	6.5%	6.2%	1.9%	0.7%	2.9%
R4,801-R9,600	15.2%	14.3%	7.9%	2.5%	8.5%
R9,601-R19,200	25.3%	23.1%	14.3%	4.1%	14.3%
R19,201-R38,400	17.8%	15.9%	22.5%	9.6%	16.8%
R38,401-R76,800	7.4%	7.7%	23.8%	18.7%	17.2%
R76,801-R153,600	2.1%	3.2%	15.2%	25.3%	14.1%
R153,601+	0.6%	2.0%	7.1%	34.8%	13.0%
Total	100%	100%	100%	100%	100%

In Site B and Site C (areas within Khayelitsha where most of the current study's sample lives) it has been estimated up to 26% of residents do not have access to formal sanitation with 105 people per toilet on average. Approximately 80% of Khayelitsha residents live in informal dwellings. Living in such conditions significantly undermines people's ability to live a healthy life. These difficulties are even more pronounced for PLWH and those on HAART who are required to access health and welfare services more frequently than the general population.

4.3 Data collection methods

The following section details the research design, data collection and data analysis processes. The choice of a mixed methods approach was informed by the need to match the complexity of the bio-psychosocial context with a dynamic and flexible research methodology.

Combining qualitative and quantitative research methodologies is becoming widely recognised as a necessity for health research, specifically relating to chronic diseases such as AIDS (Kinn and Curzio 2005). Mixed method or mixed model approaches allow for triangulation and verification of the complex and diverse sets of data, thereby facilitating a more robust analysis (Driscoll et al 2007) especially with regard to complex multi-dimensional issues such as living with HIV. Furthermore, using both quantitative and qualitative methods in a single study allows for the research to draw from their complementary strengths and mutually-exclusive

[24] Magruder and Nattrass 2005: 2

weaknesses (Johnson and Turner 2003). As Thaler notes with reference to the benefits of using mixed method approaches to the study of the complexity of violence in South Africa:

> "Mixed methods enable us to tie the broader patterns revealed by quantitative analysis to underlying processes and causal mechanisms that qualitative research is better able to illuminate, examining and explicating the interactions of structure and agency." (Thaler 2012:1)

Qualitative research and the narrative approach generate rich and detailed accounts of the lived experience, with the potential to contribute to more in-depth understandings (Neuman 2000). The qualitative aspect of this study focuses very much on the narrative of people's stories, and of how they see their HIV experience in relation to other aspects of their and other's lives. Qualitative approaches to data collection, especially those located within the ethnographic tradition, encourage researchers to become immersed in the subject matter (Miles and Huberman 1984). Whilst this admittedly might lead to bias on some level (through focusing on the intricate details of few people), it also facilitates an increased awareness and understanding of the intimate and complex nature of the subject matter. The quantitative methodology (entailing data collected through surveys) places more emphasis on measurement of statistics to achieve more generalisable findings and enables hypothesis testing in a more objective manner (Neuman 2000). Taken together, qualitative and quantitative approaches can facilitate more sensitive hypothesis construction and testing.

The qualitative aspect of the study aimed to provide a detailed understanding of those factors influencing the experiences of living with HIV/AIDS. This understanding was in turn used to develop the quantitative survey instruments. It also provided in-depth insight into the selection of variables for the quantitative analysis, and was used to shed further light and gain a deeper understanding of the quantitative analyses in Chapters 5 and 9. Conversely, the quantitative data and analysis provided important context to the women's HIV narratives and allowed me to explore the some of the key findings in the qualitative analysis amongst a much larger number of PLWH.

Throughout 2004 to 2007, I was directly involved in the design and collection of both the quantitative and qualitative data used in this dissertation. Based on a literature review and initial discussions in support groups for PLWH, the themes for investigation were identified and semi-structured interview schedules were constructed. I received valuable assistance for

conducting some of the initial qualitative interviews from a research assistant employed by the AIDS and Society Research Unit (ASRU) at the University of Cape Town (UCT). The qualitative interviews explored various themes but focussed primarily on hearing the life narratives of the respondents and their in-depth experiences of illness and HIV. In addition to the initial interviews, the qualitative data collection included many follow up conversations and discussions, participant observation in bodymap and memory box workshops and support groups over the three year period. (It is incredible how much additional insight into the data and the narratives can be gained in the thirty minute drive from central Cape Town to Khayelitsha with the women.)

The survey instruments were developed by a team of multi-disciplinary researchers, with varying research interests relating to HIV in Khayelitsha (some researchers focussed on the labour market, others on political attitudes, household dynamics etc.). The instruments included questions which could be combined to produce various scales for measuring aspects of living with HIV (e.g. experience of stigma) as well as general measures of well-being such as social support, social capital, household demographics etc. Two 'waves' of data were conducted in 2004/5 and 2006 amongst HAART patients (discussed in more detail below). In both waves of the survey, I coordinated the instrument design, training of interviewers, data collection and quality control.

In collecting data on people living with HAART, we decided to use PLWH as our interviewers. The rationale for this approach was driven by two key motives. Firstly, we hypothesised that because of the sensitive nature of the interview topics, insider-interviewers or peers would be able to obtain higher quality responses. In his review of the quality of stranger-interviewers compared with insider-interviewers in a longitudinal survey in rural Kenya, Weinreb (2006) found that insider-interviewers (i.e. from the same village and the respondents) increase response rates and collect more consistent and reliable data (ibid.:1032). Secondly, an important aspect of the research process was to train and mentor them in interviewing skills. Full-day training workshops were conducted using the survey instruments to ensure that the interviewers adequately understood the questions and were conducting the interviews in a systematic way. The research team was present during these trainings to observe practice interviews, answer questions and make recommendations on interviewing technique. This process was very important to the research team as it placed tangible value on those usually the subject of investigation by making them a critical part of the research process. All too often, PLWH are seen only as subjects under investigation, with all direct research benefits going to

the researchers and only potential long-term benefits for research participants through a trickle-down effect of changes in public policy or intervention design resulting from adopted research recommendations. PLWH were genuine collaborators in this research project. The group of research assistants and interviewers played a central role in developing the questionnaires; refining the questions and helping clarify what we were and were not asking. At those times where questionnaires had to be translated, this was particularly important, as many concepts in English or in Xhosa alike do not have the required nuance when translated. Overall, the researchers were satisfied with the final survey instrument due to the robust process in translation, discussion, back-translation, and pilot-testing, and the consistent involvement of PLWH.

4.4 Qualitative data description

Qualitative data was obtained using ethnographic approaches such as participant observation as well as in-depth interviews, self-administered questionnaires, and focus-group discussions with eleven HIV-positive African women over a number of years. They were first interviewed in early 2004 and the last interviews took place in May 2007. The sample was drawn from women who took part in the 'LongLife' AIDS-art advocacy project that was funded by MSF and ASRU.

A number of semi-structured in-depth interviews were conducted following the focus group discussions. The in-depth interviews aimed to elicit narratives of the women's unique and common experiences of living with HIV through focussing on specific relationships with significant others, sexual partners and the community. This was done primarily though probing key events directly related to disclosure and experiences of stigma, but also more general events such as the actual experience of the diagnosis itself. The interviews also probed the nature and experience of disclosure to various audiences, such as sexual partners and family members, in addition to detailed discussions on the dynamics of public disclosure and how the participants have negotiated this tricky path in particular. In order to better understand some of the issues around disclosure to sexual partners, the interview process also included a mapping exercise in which a timeline of sexual relationships was put together, in order to better understand the ways in which sexual relationships overlapped with key events in the participants HIV disease trajectory.

All interviews were conducted in English except for two interviews where another woman from the group translated from Xhosa to English. The interviews were transcribed verbatim, coded and then sorted thematically. Other than Thembi who requested that her name be used (however I decided to use a pseudonym in the interests of consistency), the other ten women requested that pseudonyms be used.

Table 4.3: Relevant details of participants in the qualitative study

Name	Age*	Education (Grade)	Marital Status*	Age at HIV Diagnosis	Date of HIV Diagnosis	Motivation for seeking an HIV test	On HAART	PMTCT
Buyiswa	28	12	Boyfriend	26	Sep-00	Pregnant	No	Yes
Dunyiswa	24	11	Single	20	Mar-00	Pregnant	No	Yes
Lizeka	26	12	Married	23	May-00	Pregnant	No	Yes
Liziwe	33	8	Single	30	Dec-98	Sick	Yes	No
Sylvia	38	11	Single	34	Jul-00	Pregnant	No	Yes
Nokwanda	35	11	Boyfriend	31	Jun-01	Sick	Yes	No
Nonceba	27	11	Single	21	Mar-00	Baby HIV+	Yes	No
Thembi	29	12	Single	26	Mar-01	Sick	Yes	No
Ntombi	33	12	Single	30	Jan-01	Sick	Yes	No
Zameka	23	9	Married	20	Mar-01	Pregnant	No	Yes
Zoliswa	31	11	Boyfriend	29	Sep-01	Sick	Yes	No
Mean	**30**	**11**		**26**			**6/11**	**5/11**

* At time of interview

4.5 Khayelitsha Select Panel Study (KSPS)[25]

HAART patients living in Khayelitsha comprise the longest surviving cohort of African HAART patients in South Africa. The Khayelitsha Select Panel Study (KSPS) was launched in October 2004 (with interviews going into early 2005). The sample was then revisited in early 2006 one year after the first wave. The survey used a snowball sampling method to question as many people as possible on HAART for longer than one year. Two hundred and forty-two respondents were recruited from clinics, HIV-treatment support groups and through word of mouth. All had received HAART through MSF's Khayelitsha pilot project. Although the sample was not random, the snowball sampling technique was able to find and include 34% of the total known cohort of people in Khayelitsha who had been on HAART for longer than a

[25] Modules from the survey instrument on disclosure and stigma are presented in Appendix C

year as part of the public sector rollout spearheaded by MSF and the Provincial Administration of the Western Cape. The individual instrument probed issues concerning labour-market participation, household income, household composition, adherence, disclosure, stigma, social and community support, traditional medicine, sexual behaviour, and health-seeking behaviour.

A group of HIV-positive fieldworkers based at the Centre for Social Science Research (who had at least one year experience in survey fieldwork) were trained to conduct the face-to-face structured interviews. Interviews lasted between 75 and 90 minutes. Completed surveys were quality controlled by a team of researchers in ASRU and surveys were then captured into a Microsoft Excel database and thereafter converted into a STATA database. Surveys were returned to field if there was missing information.

4.6 HAART panel survey sample characteristics

Table 4.4 presents the gender characteristics of the ASRU HAART sample as collected in 2004/5. The table compares the KSPS 2004/5 sample to information obtained from MSF about the gender breakdown of HAART patients in the clinic by cohort (i.e. year in which the patients started HAART). As can be seen from the table, 80% of the KSPS sample was female (n = 194). Although this seems to suggest that we had over-sampled women, the data provided by MSF (on request) reveals that HAART patients are in fact disproportionately female – perhaps because women find it easier to access care than men, especially given that many learn about their HIV status when pregnant (Nattrass 2006). Even so, the ASRU sample contains relatively more women in total (80%) than is the case in the MSF clinic (70%).

Table 4.4: Gender characteristics of KSPS 2004/5 sample compared to data from the MSF clinic

Cohort	**2001**	**2002**	**2003**	**2004**	**Total**
KSPS					
Male (n)	10	11	21	6	48
Female (n)	41(80%)	42 (79%)	73 (78%)	38 (86%)	194 (80%)
Total	51	53	94	44	242
MSF					
Male (n)	23	62	118	319	522
Female (n)	57 (71%)	143 (70%)	266 (69%)	743 (70%)	1209 (70%)
Total	80	205	384	1062	1731

Source: KSPS Data (from ASRU); MSF clinic data (provided by MSF on request)

There were 242 respondents in 2004/5 and 224 in 2006 (a 7.4% attrition rate of 18 respondents between the two waves). Of the 18 respondents who had attritted, two had died, ten had moved and six could not be found (and no information about them could be obtained) – see Table 4.6. On average, the demographic characteristics of KSPS 2006 showed that a higher proportion of respondents reported being in wage or self-employment and fewer respondents reported receiving the disability grant.[26] Respondents in the KSPS 2006 survey also reported higher levels of self-reported health status.

The men in the KSPS 2004/5 sample are slightly older than the women in the sample which is comparable to other treatment cohorts in South Africa and in Southern Africa more broadly. In the ART-LINC Multi-Centre Research Collaboration, Braitstein et al (2008: 53) found that more women than men access HAART in low-income countries partaking in the study. Data disaggregated by sex show that adult women are advantaged over adult men in access to HAART in low- and middle-income countries. About 60% of adults receiving HAART in reporting countries were women, who represent 55% of the people in need (UNAIDS 2009). Similarly Muula et al (2007) found in their systematic review of 13 HAART programmes in Southern Africa, that in ten of the country studies reviewed, more the female to male ratio of HAART access was >1 (ibid:3). Nattrass (2008c) found that women accessed health services more often than men, but that this gender difference was particularly strong with regards to HAART coverage.

Women on average have one year more education than their male counterparts, yet the low levels of employment are similar in magnitude. The majority of respondents have some income with over 70% receiving disability grants (valued at ZAR 740.00 per month at the time of the interviews). Women also seem to have known their HIV status for slightly longer than the men, with the total average of time since diagnosis being just over four years (50 months). On average, both men and women have been on HAART for a similar period of just over two years.

Self-reported health status shows that women report better perceptions of their own health than men in the KSPS sample, with 16% more women reporting excellent health than men, and 4%

[26] This is to be expected as government disability grants need to be renewed, and once a patients are stabilised on HAART, they are deemed to be healthy enough to work and no longer eligible for the disability grant. Venkataramani et al (2010) have shown that this loss of income was compensated in part by higher employment rates, and that despite the loss of income, the HAART patients did not subsequently default on their treatment in order to get the grant restored.

more men reporting poor or fair health than women.[27] The gender bias in the sample is comparable to other research samples from other Southern African contexts (e.g. Wong et al 2009 in South Africa and Ochieng et al 2008 in Kenya), where for example, a study with 65,000 patients at 18 sites in Kenya found that men were more likely to be WHO stage three or four, with lower CD4 counts, and less likely to have disclosed their HIV status (Ochieng et al., 2008; see also Makwiza et al., 2009 Sebuliba et al., 2008 Kirungi et al., 2008).

Table 4.5: Key characteristics of KSPS survey sample (column percentages)

2004/5	**n**	**Total**	**2006**	n	Total
N		242	N		224
Female	194	80%		183	82%
Employed - wage or self (mean)	80	33%	Employed - wage or self (mean)	95	42%
Education (0-12yrs) (mean)		9.5	Education (0-12yrs) (mean)		9.6
Age (mean)		34	Age (mean)		35
Age at diagnosis (mean)		30	Age at diagnosis (mean)		30
Age at diagnosis (median)		28	Age at diagnosis (median)		28
Disability Grant Recipient	178	73%	Disability Grant Recipient	104	46%
Months since diagnosis (mean)		50	Months since diagnosis (mean)		64
Months on ART (mean)		24	Months on ART (mean)		39
Health			**Health**		
Poor or fair health	32	13%	Poor or fair health	26	12%
Excellent health	82	34%	Excellent health	56	25%
Clinic			**Clinic**		
Site B	104	43%	Site B	97	43%
Nolungile/Site C	100	41%	Nolungile/Site C	90	40%
Michael M	34	14%	Michael M	27	12%
Other	4	2%	Other	10	5%

Table 4.6 presents the results of an attrition analysis. A significantly higher proportion of women attritted than men. Only 11% of attritors reported being wage or self-employed in 2004/5 while 35% of respondents reported being wage or self-employed in the general sample. The sample therefore lost a disproportionate amount of unemployed respondents. The sample also lost the less-educated with a mean difference of 1.9 years of education. Attritors were on average 6.4 years older than the rest of the sample, and had known their HIV-positive status

[27] 'Poor or fair health' represents a dummy variable for those people who responded poor or fair to the question "In general, how is your health? Would you say it is poor, fair, good very good, or excellent? The same applies to the 'excellent health' variable. In her analysis of the data from the MSF clinic Coetzee (2005) showed that self-perceptions of health track clinical markers such as CD4 and viral load counts. Even though the KSPS survey did not have access to the patient clinical data, perceptions of health may therefore still be used as an indicator of health status.

for, on average, 6.4 months longer. A higher percentage of attritors had disability grants (11% more), yet this was not a statistically significant difference. In terms of disclosure to sexual partners, the analysis shows that there were not statistical differences between attritors and non-attritors.

There was no substantial difference between samples (attritors versus non-attritors) for months since diagnosis and months on HAART. However, there was a significant difference between attritors and non-attritors for self-reported health status, where 33% of attritors reported poor or fair health in the 2004/5 survey compared to 12% of non-attritors.

In terms of the psycho-social indices (the 'depression/anxiety scale'[28] and the 'self-concealment scale'[29]) the analysis shows differences between attritors and non-attritors. In terms of depression/anxiety, attritors scored 2.3 units higher on the scale than those surveyed in 2006. Attritors also scored 1.4 units lower on the self-concealment scale i.e. they conceal more. In summary, the survey lost respondents were unemployed, older, less educated, had known their HIV-positive status for longer, had poorer health (self-reported), were more depressed or anxious and concealed more of their problems. We know that two of the attritors had died, and it is likely that some of those about whom we could get no information had also died.

[28] Questions selected and adapted from the Virginia Commonwealth University and Rhodes University Eastern Cape Pilot Survey, 2004

[29] Questions selected from Kahn, J. and R. Hessling. 2001. "Measuring the Tendency to Conceal versus Disclose Psychological Distress", in *Journal of Social and Clinical Psychology*, no.20.

Table 4.6: Attrition analysis between KSPS 2004/5 and 2006 survey waves

Attrition – 2004/5 – 2006	Attritted 7.4%, 18 respondents			
	No	**Yes**	**Total**	**P-value**
N	224	18	242	
Gender				P = 0.059*
Male	18%	39%	19%	
Female	81%	61%	80%	
Employed - wage or self (mean)	35%	11%		P = 0.040*
Education (0-12yrs) (mean)	10	8	9	P = 0.0079**
Difference			2	
Age (mean)	33	40	34	P = 0.0005***
Age at diagnosis (mean)	30	36	30	P = 0.0004***
Disability Grant Recipient	73%	83%	74%	P = 0.415
Months since diagnosis (mean)	50	48	50	P = 0.7526
Months on ART (mean)	25	23	24	P = 0.4681
Health				
Current health status (1 poor - 5 excellent)	4	3	4	P = 0.0557*
Poor or fair health	12%	33%	13%	P = 0.021*
Excellent health	35%	22%	34%	P = 0.315
Site				P = 0.316
Site B	43%	47%	43%	
Nolungile/Site C	15%	0%	14%	
Michael M	40%	53%	41%	
Other	2%	0%	2%	
Disclosure				
Disclosed to sexual partner (n=196)	88%	83%	87%	P=0.654

* p<0.1; ** p<0.01; *** p <0.001
Numbers have been rounded

4.7 Study limitations

There are several limitations to this study. Firstly, information received was self-reported and therefore could not be verified. This is acceptable for many of the attitudinal, belief or experience variables, yet it would be more accurate having clinical data to verify the health-related variables, as well as being able to use clinical data within the analysis.

Secondly, due to the snowball sampling method, the data may not be generalisable to the wider population of HAART patients. However, as we managed to sample two thirds of the starting cohort (51/80 – see Table 4.4), the trends and patterns are likely to be sufficiently representative for this cohort that we can draw meaningful conclusions about them from the data. Thirdly, the sample was drawn from people in the MSF HAART programme, which is therefore not representative of people on HAART only through the public sector. It may

however be comparable to other NGO-supported HAART provision such as that by Absolute Return for Kids and Desmond Tutu HIV Foundation. To the extent that clinical outcomes may reflect potentially superior service provision in the MSF clinics, the results will accordingly not be representative of people in other programmes.

Face-to-face interviews are also a research methodology that carries both benefits and costs. As described above, the face-to-face interviews allows for more spontaneous and robust data gathering where the interviewer is able to probe, reframe and clarify questions during the interview process. However, there are costs associated with face-to-face interviews, in particular, those related to subjectivity of the researcher or interviewer where different interviewers may direct the conversation according to their interpretation of body language and the nuance of particular answers. The sensitive nature of face-to-face interviews may also pose a problem where respondents may feel constrained for a range of reasons (possibly relating to race, gender, HIV status) to 'open up' to the interviewer.

Language often posed a problem in both the qualitative and quantitative research methodologies. In the case of the qualitative interviews, the problems could more easily be overcome through rephrasing or repeating questions. However, the fact that English is in most cases, either a second or third language for respondents made interviews quite challenging. This, coupled with possible misinterpretation during translation, is grounds for caution. Even so, a great deal of attention was paid to ensuring that study participants were understood correctly.

The gender bias of the survey towards women also poses a limitation on the generalisability of the survey findings. As argued in Chapter 2, because women bear a disproportionate brunt of the AIDS epidemic, it is important that we understand the specific challenges faced by women in order to design better support and clinical interventions. However, as the others chapters will show, women's decision making is often constrained and significantly influenced by men. However, due to the snowball sampling method, which used clinic-based HIV support groups to locate respondents, fewer men were included in the sample as men attend clinics less frequently than women and support groups generally cater for women.

4.8 Ethical considerations

Every effort was made to ensure that the participants in the research and the fieldworkers who supported the research were protected from harm. Harm in this case could have arisen from the disclosure of private information collected during the research process, especially of participants' HIV-positive status and other sensitive information about participant's private lives. Discussions were held in the CSSR and ASRU about this, and as mentioned earlier, ethical approval was obtained from the CSSR Ethics Committee for the KSPS Study which covered both quantitative and qualitative data collection. As the qualitative research adopted an ethnographic research approach, informed consent was constantly negotiated with research participants over the length of time the research took place. This constant negotiation was important as some people may have given consent at a particular point in time, but because of the length of the research period, their life circumstances may have changed e.g. starting a new sexual relationship. It was therefore agreed with all qualitative research participants, in the context of in-depth interviews and participant observation of support groups, to guarantee anonymity where possible and use pseudonyms.

The research team put significant effort into the development of consent forms for the study and the training of fieldworkers in their own understanding of the consent process and the need to ensure that participants adequately understood the consent process. Standard consent forms were therefore redesigned with a 'question-answer' approach rather than an information only approach.[30] Considering that a large part of the research, in both the qualitative and qualitative elements was about AIDS-stigma and disclosure, extra care was taken to inform participants of where and how the data was to be used. This was also important as our pilot research, and that of previous studies, showed that participants are often not willing to give accurate details of their personal lives and choices, particularly when they relate to such intimate aspects of their lives and which information could potentially put them at significant risk. A clear example such risks is the question of whether a participant had disclosed to their sexual partner and whether they use condoms on a regular basis. Surveys were kept in a locked room in a locked office at the University of Cape Town, and the research management team ensured that strict monitoring and tracking systems were in place to ensure that surveys that left the office (for quality control purposes) were returned.

[30] See Appendix A for a copy of the consent form

All respondents who participated in the KSPS survey were given a token of appreciation for their participation, for example a cloth shopping bag or a peak caps. Through feedback from the fieldworkers, the token of appreciation was changed to food vouchers (a more general token) as this was less identifiable than a specific gift. This kind of continuous learning and risk assessment was important in order minimise the risk of involuntary or third-party disclosure, that could, ironically, be caused by a research project on disclosure.

The safety of fieldworkers was also taken into account. During training and throughout the research process, fieldworkers were provided with the resources (mobile phone airtime, travel support) to be able to plan their interviews with respondents after initial contact had been made. In cases where fieldworkers were unsure of respondents' addresses, fieldworkers were encouraged to go in pairs. Transport costs were covered in all instances.

Chapter 5: The experience of stigma: evidence from a survey of PLWH on HAART in Khayelitsha

Chapter 3 reviewed the South African and international literature indicating that fear of negative consequences resulting from stigmatising attitudes and behaviours towards PLWH is a major factor limiting people's willingness to disclose. This is especially problematic when the potential disclosure recipient is a household member or close friend - people who are trusted the most and are usually relied upon for important support and care. Further on in the thesis, Chapters 6 and 7 employ qualitative methods to explore the complex dynamics of disclosure to 'the public' as well as to significant others at the household level amongst the group of HIV-positive activist women in Khayelitsha. Fear of stigma, or specific behaviours such as gossip, is a persistent theme in that analysis. This chapter sketches the broader context for the qualitative analysis that follows by presenting relevant quantitative data on the experience of stigma amongst a wider sample of over 200 PLWH on HAART from the KSPS survey in Khayelitsha (described in Chapter 4). Sketching the broader social context is important because one of the findings from the qualitative arm of the study is that even though the fear of stigma was pervasive, the narratives of disclosure revealed a generally supportive environment in the household. This raises the question as to whether the participants in qualitative arm of the research – who were a fairly select group of activist-oriented PLWH, were broadly similar to or very different from the wider group of PLWH captured in the KSPS surveys. The KSPS survey data allows us to explore this particular question.

As discussed in Chapter 3, it is possible to identify various dimensions of stigma, all of which are important to consider in the analysis of the experience of living with HIV, including instrumentally driven, symbolically driven, and behavioural intentions towards PLWH. From the perspective of PLWH, the experience of stigma may take the form of actual negative experiences (experienced stigma), perceived stigma, and internalised stigma. (Note that the breakdown of stigma into its instrumental and symbolic concepts is less useful when looking at disclosure to sexual partners, as important contextual factors such as gender and power relations may hold more sway on people's decision making and the responses to disclosure. Disclosure to sexual partners is considered in some depth in Chapters 8 and 9.)

The notion of internalised-stigma rests on the idea that even though stigma is a socially and culturally determined phenomenon, it is experienced and processed at the level of the individual often leading to depression or other mental health problems (Wight 2000; Kalichman et al 2005). The psychological processes involved in internalised stigma result in individuals devaluing themselves as a result of their devalued social status in the eyes of the broader society (Joffe 1999) through processes of self-blame and self-depreciation (Simbayi et al 2007b). Simbayi et al (2007b) measured internalised stigma amongst PLWH in Cape Town and its links to depression. The researchers found that PLWH who have higher rates of internalised stigma, are also more likely to have symptoms of depression (2007b:1829). Internal stigma dialogues with Goffman's notion of a spoiled identity (Goffman 1963). As Joffe notes: "Spoiled identity indicates that dominant ideas can enter the psyche and make for subjective feelings of self-disgust" (1999: 54). It must however be pointed out that the increased likelihood of depression amongst PLWH is not exclusively a result of HIV and HIV-related stigma, but has also been shown to be a result of the experience of living in poverty (Brandt 2007). Brandt's finding also talks to the Simbayi et al finding above, in that there may also be a bi-directional relationship between internal stigma and depression – where people who are more likely to be depressed due to the effects of living in poverty being more likely to experience higher levels of internalised stigma, and the reverse occurring where internalised stigma leads to increased depression.

While internalised stigma relates to how PLWH see themselves in relation to their HIV status and how they think HIV is viewed by the broader social context, perceived stigma refers to the perceptions of PLWH about the broader stigmatising environment in which they are located. Perceived stigma, in other words, is the expectation that one would be stigmatised by others as a result of how much one believes the public stigmatizes someone with HIV (Derlega 2002). In terms of disclosure, perceived stigma has a significant impact on the decision making process as it is the individual's subjective assessment of the level of risk associated with being identified as HIV-positive. Such perceptions are often fuelled by stories the individual may have heard about others' experiences and often leads to PLWH feeling that they live in a world with pervasive stigma (Chandra et al 2003, Schmidt and Goggin 2002). These perceptions often overestimate the actual risk, as demonstrated by a number of studies in both the developed (Swendeman et al 2005) and developing world (Visser 2004; Chandra et al 2003; Greeff et al 2010) that have looked at the relationship between perceived stigma and actual experiences of stigma. For example, a study from south India reported that 97% of HIV-positive respondents reported perceived stigma, but only 26% actually experienced negative

reactions to being discovered as HIV-positive (Thomas et al, 2005). However, as mentioned above, despite the disjuncture between perceived and experienced stigma, studies do show that the perceived negative reaction to disclosure actively discourages important behaviour such as HIV testing, it exacerbates the psychological difficulties associated with keeping one's HIV-status a secret, and ultimately leads to a reduced quality of life (Greeff et al 2010). In a study of over 1,500 women in rural Kenya, women who anticipated negative responses from their male partners to disclosure were more than twice as likely to refuse HIV testing, even after adjusting for other individual-level predictors (Turan et al 2011).

Actual negative experiences or 'experienced stigma' relating being identified as HIV-positive are seen as a result of the behavioural manifestations of stigmatising attitudes, ideas and beliefs. To put it in 'stigma' terminology, experienced stigma is the result of enacted stigma (on the part of others) (Deacon et al 2005:20). The term 'behavioural' is critical when discussing behavioural manifestations, as stigmatising intentions, beliefs or attitudes may not actually manifest in behaviour and therefore may not be a problem for PLWH. The importance of this distinction is in the fact that many studies attempting to measure AIDS-stigma use behavioural intentions as the proxy measure for actual behaviour (Maughan Brown 2008:45).

The following section quantifies the various dimensions of stigma experienced, internalised and perceived by PLWH in Khayelitsha using the KSPS 2004/5 and 2006 survey data. Firstly, the analysis describes the various ways in which data on stigma was collected in the KSPS surveys. The analysis then explores the multiple dimensions of stigma using both the KSPS 2004/5 and 2006 datasets (where possible) and then also explores changes in stigma over time where the data allows for such analysis. The chapter then moves on towards investigating the relationship between stigma and other important factors, such as health status and being on HAART, and importantly the relationship between stigma and disclosure. Finally, the analysis uses multivariate methods to investigate the determinants of experienced stigma.

5.1 Measures

Experienced stigma

In order to quantify respondents' experiences of stigma, the survey measured stigma in various ways. The analysis also uses longitudinal data from the KSPS 2004/5 and KSPS 2006 surveys to gain a sense of changes in experiences of stigma over time. However, due to the wording of the questions, we are unable to make definitive conclusions about changes over time. This is a

result of the wording of the questions in KSPS 2004/5 which asked about all previous experiences prior to the survey, where the wording in KSPS 2006 referred to the time period between the surveys.

The survey asked about specific kinds of negative experiences as a result of HIV, specifically the extent to which respondents agreed or disagreed with eight statements (see Table 5.1). The response options were based on a 5-point Likert scale from 'Strongly disagree' to 'Strongly Agree'. The Experience Stigma Scales for 2004/5 and 2006 were constructed by adding up the responses to the eight items resulting in a score from 1 – 64. Using Cronbach's Alpha as a measure to test the consistency in the responses to the items that make up the index, we were able to see that the scales were reliable (2004/5 scale α =0.81; 2006 scale α=0.91).

The response options to the stigma items in Table 5.1 were also transformed into a dummy variable taking the value of one for 'experienced stigma' and zero for 'experienced no stigma. The 'experienced stigma' value was given a value of one if the respondent selected either 'neither agree or disagree', 'agree' or 'strongly agree'. 'Neither agree nor disagree' was interpreted as meaning 'some of the time' and thus included in the 'agree' column. The rationale for this was based on conversations with the fieldworkers in which they said that respondents could not definitively say whether their experiences were due to negative attitudes, perceptions or beliefs as a result of their HIV-status so the respondent just reported 'neither agree nor disagree'. Including 'neither agree nor disagree' as a potential indicator of stigma is important as even though people may not be sure if others behaviour may or may not be due to their HIV status, their ambivalence may lead to behaviours that aim to mitigate the risk of potentially stigmatising situations. This variable construct is used in the transition analysis in Figure 5.1 and Table 5.9. In Figure 5.1, each respondent got a score from zero to eight by adding together the dummy variables described above. The transition analysis in Table 5.9 is based on a new dummy variable where each respondent received a value of one if they reported experiencing any of the eight stigma items.

The final measure of experienced stigma was a more direct and general measure. Interviewers were also asked to describe stigma to the respondents in the following way: "Stigma refers to horrible things that people think about, say to or do to you or your family because you have HIV. Stigma also refers to when people stop thinking, saying or doing nice things about/to you or your family because you have HIV." Respondents were then asked if they had ever experienced stigma, and if they had, how often, by whom and differences between experiences

when they were healthy compared when they were sick. This data is presented in the results section below. The dummy variable measuring whether respondents 'ever experienced stigma' is used as the dependant variable in the multivariate analysis.

Table 5.1: Items used to measure experiences of stigma

1	I have lost friends because I am HIV positive
2	Family members and friends have treated me badly because I am HIV positive
3	When people find out I am HIV positive, they feel uncomfortable in my presence
4	People are concerned that they could 'catch' HIV from the food I prepare or from touching me
5	People who have no reason to fear still worry that they will catch HIV from me
6	People treat me with less respect when they find out I am HIV positive
7	Because I am HIV positive, people say unkind things behind my back
8	Many people avoid me because I am HIV positive

Perceived HIV-stigma

As described above, the perception that one lives within a stigmatising context (perceived stigma) is a major constraint to disclosure. Perceived stigma is also likely to constrain behaviours that one might think could lead to being identified as HIV-positive even if there is often a disjuncture between perceived stigma and actual experiences of stigma i.e. PLWH often think that there is more stigma than there actually is. The KSPS 2004/5 survey included four items that aimed to obtain a measure of the levels of perceived stigma amongst PLWH on HAART in Khayelitsha (Table 5.2). The response option was based on the five-point Likert scale from 'strongly disagree' to 'strongly agree'. The scale was constructed by adding responses. Using Cronbach's Alpha to test for the scale's internal consistency (i.e. if the questions were measuring the same thing), of the four items measuring perceived stigma, we were able to see that the responses did not seem to be measuring the same thing (2004/5 scale α =0.52). However, items 2 and 3 showed a greater level of internal consistency (α =0.62).

Table 5.2: Items used to measure perceived stigma

1	Most people with HIV are supported by their families when they disclose their HIV status
2	People with HIV often get treated unfairly or badly by others
3	People say unkind things about HIV positive people
4	Most people prefer to avoid people with HIV as much as possible

Internalised HIV-stigma

The survey also explored the concept of internalised stigma using a number of questions tested by in the Centre for Health Systems Research and Development Survey (see Berger et al 2001). Table 5.3 lists the statements of which survey respondents were asked the extent to which they agreed or disagreed. To test that the items were measuring the same thing (as was done for the perceived stigma items above), statements 1 and 3 were inverted so that the responses to all items were consistent. The Cronbach's Alpha test showed that the combination of internal stigma items was reliable ($\alpha = 0.74$).

Table 5.3: Items used to measure internalised stigma

1	I never feel ashamed of having HIV.
2	HIV makes me feel like a bad person.
3	I feel I am just as good as others who are HIV negative.
4	Having HIV makes me feel unclean.
5	People's attitudes about HIV make me feel worse about myself.
6	I feel guilty because I have HIV.
7	HIV/AIDS is punishment for bad behaviour.

Depression and Anxiety

As discussed in Chapter 3, the experience of living with HIV is at once a physical, social and psychological experience. Research amongst poor women in Cape Town has shown that PLWH are at increased risk of mental health problems when compared to their HIV-negative counterparts, often (but not exclusively) caused by the impact of stigma on the individual (Kahn, 2005; Kalichman 1995). Both the KSPS 2004/5 and 2006 surveys therefore included a measure of depression and anxiety using five questions from the Virginia Commonwealth University and Rhodes University Eastern Cape Pilot Survey (2004) – see Table 5.4. The responses were based on a five-point Likert scale from 'Never' to 'All the time'. The Depression/Anxiety Scale was constructed through simply adding the responses to the five questions creating a scale from 0 to 25 (with 25 representing the highest level of depression/anxiety). As with previous scales/indices, Cronbach's alpha was used to test for internal consistency ($\alpha = 0.79$ in KSPS 2004/5 and $\alpha = 0.84$ in KSPS 2006).

Table 5.4: Items used to measure depression/anxiety

	In the past year how often have you:
1	Felt that problems are piling up so high that you cannot overcome them?
2	Felt that you cannot stop feeling very sad and depressed – even with help from your friends or family?
3	Felt lonely?
4	Felt nervous or stressed?
5	Been so worried or anxious that you have felt tired, worn out or exhausted

Validation of constructs

Before the chapter moves on to explore the results of the analysis of stigma in detail, it is important to validate the constructs through testing the direction of correlation between experienced stigma, internalised stigma and depression/anxiety. In other words, it was hypothesised that stigma scores would be positively correlated with the depression/anxiety score as a result of both the experience and internalisation of stigma leading to mental health problems. Table 5.5 below displays a correlation matrix for both survey waves and includes the Experience Stigma Scale, the Internalised Stigma Scale and the Depression/Anxiety Scale. The results show that the correlations are consistently positive in both survey waves between the three scales, providing further evidence for the validity of the stigma constructs. It is important to note however the decrease in the correlation coefficients in KSPS 2006 compared with 2004/5 which may be reflecting the general decrease in scores across almost all indices in the KSPS 2006 survey.

Table 5.5: Correlation matrix to validate stigma constructs using KSPS 2004/5 and 2006

	KSPS 2004/5				KSPS 2006		
	Depression/ Anxiety	Experience Stigma	Internal Stigma		Depression/ Anxiety	Experience Stigma	Internal Stigma
Depression/Anxiety	1				1		
Experience Stigma	0.43	1			0.12	1	
Internal Stigma	0.23	0.43	1		0.19	0.35	1

5.2 Results

The survey data from KSPS 2004/5 on the various stigma measures show some level of stigma perceived, experienced or internalised by PLWH in Khayelitsha. The data on perceived stigma shows that the PLWH overwhelmingly think that other PLWH are supported by their families when they disclose their HIV status (see Table 5.6). This may be a result of their own

disclosure experiences where both the qualitative analysis in Chapter 7 and the quantitative data in Chapter 9 show high levels of support when PLWH disclosed to carefully selected family or household members. However, the data also shows that the majority of the KSPS survey respondents either agree or strongly agree that PLWH get treated badly or unfairly by others and that PLWH are gossiped about. The sections below, as well as the qualitative analysis that follows in Chapters 6, 7 and 8, show that gossip consistently features as the dominant form of stigma actually experienced by PLWH. Thus it is understandable why so many respondents perceive this to be the case with other PLWH. The data also shows some level of internalised stigma with 23% of respondents reporting that they either agree or strongly agree with the statement 'having HIV makes me feel unclean', and 22% of respondents who agree or strongly agree with the statement 'I feel guilty because I have HIV' (see Table 5.7).

Table 5.6: Perceived Stigma Questions and Responses from KSPS 2004/5

	Please tell us how strongly you agree or disagree with the following statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	Most people with HIV are supported by their families when they disclose their HIV status	0% (0)	3% (6)	36% (86)	52% (126)	10% (24)
2	People with HIV often get treated unfairly or badly by others	1% (2)	5% (13)	37% (90)	46% (112)	10% (25)
3	People say unkind things about HIV positive people	1% (1)	6% (14)	27% (66)	56% (136)	10% (25)
4	Most people prefer to avoid people with HIV as much as possible	1% (2)	9% (21)	60% (142)	24% (56)	6% (15)

Note: Numbers in parentheses indicate the number of respondents; percentages do not always total 100% due to rounding effects

Table 5.7: Internalised Stigma Questions and Responses from KSPS 2004/5

	To what extent do you agree or disagree with the following?	Strongly Disagree	Disagree	Agree	Strongly Agree
1	I never feel ashamed of having HIV.	15% (34)	34% (76)	33% (75)	16% (37)
2	HIV makes me feel like a bad person.	45% (100)	38% (84)	15% (34)	2% (5)
3	I feel I am just as good as others who are HIV negative.	3% (7)	12% (27)	26% (57)	60% (132)
4	Having HIV makes me feel unclean.	41% (92)	36% (80)	17% (37)	6% (14)
5	People's attitudes about HIV make me feel worse about myself.	30% (66)	54% (121)	11% (25)	5% (12)
6	I feel guilty because I have HIV.	30% (68)	48% (108)	18% (40)	4% (8)
7	HIV/AIDS is punishment for bad behaviour.	43% (91)	47% (100)	9% (18)	2% (4)

Note: Numbers in parentheses indicate the number of respondents; percentages do not always total 100% due to rounding effects

5.3 Changes in experienced stigma prior to 2004/5 and between 2004/5 and 2006 surveys

The data suggests that negative social and inter-personal experiences related to HIV were lower in the time between the 2004/5 and 2006 interviews compared to pre-2004/5 (see Table 5.8). This implies that either the social environment had become less stigmatising, or that the PLWH had managed to find more socially supportive and less stigmatising social circles to live in. Five of the eight experiences asked about in the survey showed such decreases. The most significant change was measured in the statement, "People say unkind things behind my back", which aimed to capture experiences of gossip. Two thirds of respondents in 2004/5 reported gossip while 34% of respondents reported experiencing gossip between survey waves. Even though the change is significant, the fact that 34% of respondents continued to report experiencing gossip is problematic. In terms of the broader context, the reduction in experiences of stigma runs counter to other survey data from Cape Town from the CAPS Study (Cape Area Panel Study). CAPS surveyed over 1,000 young adults in the general population in Cape Town between 2003 and 2006 and asked questions probing stigmatising attitudes and behaviours. Using the CAPS survey data, Maughan-Brown (2009:371) found that stigma had actually increased over time as measured using multiple dimensions of stigma. For example, 21% of respondents in 2003 reported that they would not drink from the same bottle as an HIV-infected friend he found that respondents, increasing to 43% of respondents in 2006 ($p<0.01$).

As a reflection of changes in symbolic stigma, he also found, for example, a significant increase in the percentage of respondents thinking that HIV/AIDS is punishment for sleeping around, and in a separate question, have only themselves to blame ($p<0.01$). The difference between Maughan-Brown's findings and that of this study may well reflect the unique nature of the KSPS sample – i.e. that many are activists, and are linked into support groups, and have therefore an increased probability of encountering stigmatising attitudes, especially at the height of activism between 1999 and 2004 when public disclosure was commonplace amongst TAC activists, many of whom were likely to be respondents in the survey (even though this was not asked specifically but was confirmed by the research fieldworkers).

Instrumental stigma, captured by the statement "People who have no reason to fear still worry that they will catch HIV from me", also decreased between surveys compared to pre-2004/5. Even though respondents report that fears of infection are less of a concern that previously, the fact that 22% of respondents continue to report that potentially unwarranted fears of infection is concerning. The persistence of instrumental stigma is also reflected by the increase in respondents reporting that other people are concerned that they could catch HIV from the food they prepare or from touching them (10% to 13%) although this increase was not statistically significant.

Table 5.8: Experiences of stigma prior to the HAART 2004/5 survey and between the 2004/5 and 2006 surveys.

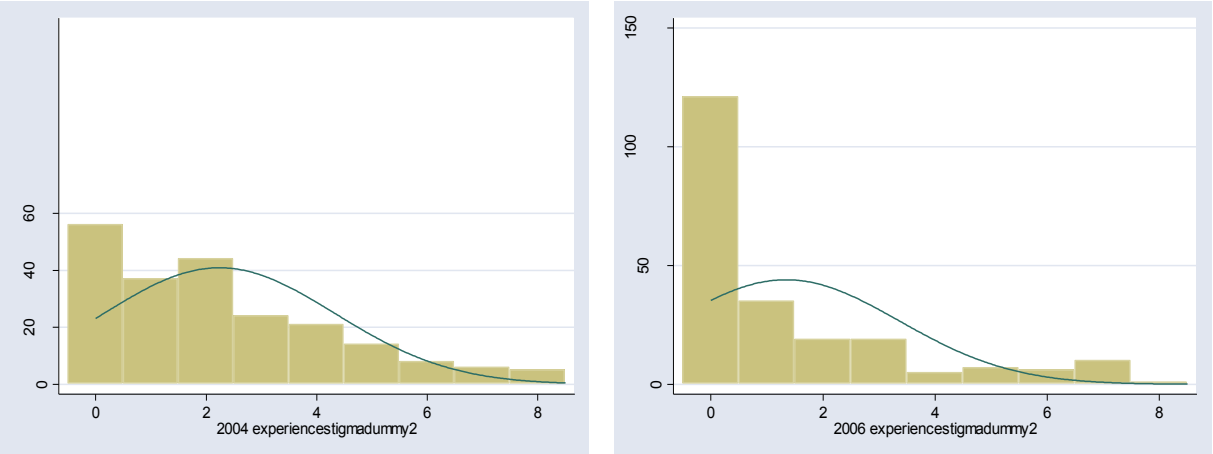
	To what extent to you agree or disagree with the following?	Before 2004/5 (n=242)		Between 2004/5 and 2006 (n=224)		t-test	Stuart-Maxwell Chi sq.[31]
		Disagree	Agree	Disagree	Agree		
1	I have lost friends because I am HIV positive	84%	16%	88%	12%	1.31	1.28
2	Family members and friends have treated me badly because I am HIV positive	93%	6%	93%	7%	-0.22	0
3	When people find out I am HIV positive, they feel uncomfortable in my presence	70%	30%	83%	17%	3.38***	11.2***
4	People are concerned that they could 'catch' HIV from the food I prepare or from touching me	80%	10%	87%	13%	1.83*	2.4
5	People who have no reason to fear still worry that they will catch HIV from me	55%	45%	78%	22%	5.43***	23.31***
6	People treat me with less respect when they find out I am HIV positive	82%	18%	89%	11%	2.13**	4.25**
7	Because I am HIV positive, people say unkind things behind my back	33%	67%	66%	34%	7.42***	45.47***
8	Many people avoid me because I am HIV positive	73%	27%	83%	17%	2.58**	7.12***

Note: percentages do not always total 100% due to rounding effects

The individual items measuring experienced stigma (using the dummy/binary variables described above) were summed to form an overall experience of stigma index (0 – 8). Zero represents no stigma, while eight represents the most stigma (i.e. experienced at least one of every type of experience probed in the questionnaire). Figure 5.1 shows histograms of the experience of stigma index by survey wave. The figures show that the distribution of people reporting experiences of stigma shifted left (towards no experiences) over time due to an extra 82 respondents reporting not experiencing any form of stigmatising behaviour. Using the Stuart-Maxwell chi-squared test we can see that this graphical change was indeed statistically significant (chi2=46.23; $p<0.001$). The data on adherence also shows a decrease in the effects of stigma on respondents' adherence. In KSPS 2004/5, 14% of respondents reported that they missed taking their pills because they did not want others to see them taking their medication. In KSPS 2006 however, only 4% of respondents reported missing taking their ARVs for this reason.

[31] The Stuart-Maxwell Chi-squared test is used to test the homogeneity of the marginal distribution i.e. do the two populations come from the same distribution functions. A statistically significant value shows that the distribution functions are indeed different. I have used both paired t-tests and Stuart-Maxwell tests in order to gauge whether changes between pre-2004/5 and between 2004/5 and 2006 are indeed actual changes or merely changes in the overall means (as is shown in a paired t-test).

Figure 5.1: Experience of Stigma Scale – pre-2004/5 and between 2004/5 and 2006



Note: X-axis represents number of stigmatising experiences reported by respondents (0-8). Y-axis represents the number of respondents reporting.

A transition analysis (Table 5.9) was conducted in order to explore further the changes in stigma experienced by respondents between the surveys. Even though 82 fewer respondents reported experiencing stigma in 2006, 10% of respondents experienced more stigma between 2004/5 and 2006 compared to the period pre-2004/5 survey and a further 76 respondents reported experiencing some form of stigma pre-2004/5 and between surveys.

Table 5.9: Transition analysis of experiences of stigma pre-2004/4 and between 2004/5 and 2006:

Transition	n	Percent
Experienced no stigma in both waves	35	16%
Experienced no stigma in pre-2004/5 and stigma between 2004/5 & 2006	21	10%
Experienced stigma in pre-2004/5 but not between 2004/5 & 2006	82	38%
Experienced stigma in both waves (1→1)	76	36%
Total	214[32]	100%

Note: Numbers percentages do not always total 100% due to rounding effects

5.4 The relationship between health status and experiences of HIV-stigma

In the qualitative analysis in Chapters 6 and 7, the women frequently described experiencing stigma more often when they were sick and when they were showing visible signs of illness, dovetailing with Alonzo and Reynolds' (1995) concept of a 'stigma trajectory'. The KSPS

[32] The dataset includes full data for 214 of the 224 respondents from KSPS 2006 i.e. no missing observations in all eight stigma measures.

2006 survey therefore included questions on experiences of stigma when the respondents were sick (i.e. prior to starting HAART), and in the three months prior to the survey. Table 5.10 displays the results.

Based on the assumption that respondents' health in the three months prior to the survey was fair, good or excellent (as indicated by only 11% reporting poor health in the three months prior to the 2006 survey), the data suggests that people experienced fewer stigmatising episodes in the three months prior to the 2006 survey compared to when they were sick just before they were beginning HAART. In other words, it seems as if experienced stigma may have decreased as people's health was restored on HAART (which no doubt had both psychological and physical benefits). However, these findings need to be interpreted with caution, as the average duration on HAART for respondents was 39 months in KSPS 2006. The social context of HIV/AIDS in Khayelitsha was likely significantly different when respondents started HAART compared with the context in 2005/6 (prior to the survey). Thus, the reductions in reports of experiences of stigma may be related to a less-stigmatising environment (as indicated by a reduction in reports of gossip) and the fact that people may have already disclosed to everybody they wanted to rather than a relationship between health status and stigma.

For those respondents that reported being gossiped about, they were asked to identify the individual or group that does the gossiping, both at the time they were sick prior to beginning HAART and in the three months prior to the survey. As was the case in overall experiences of stigma at the two time points, Table 5.11 shows that the numbers of people that reported being gossiped about decreased from 75 when respondents were sick to 22 in the three months prior to the survey. Neighbours and people living in one's street are the cause of the majority of gossip, followed by friends. Despite the data suggesting that gossip may have decreased over time, the fact that PLWH continue to report that close family members and other relatives gossiping as a result of their HIV status is worrying.

Table 5.10: Specific experiences of stigma when respondents were sick prior to starting HAART and in the three months prior to the 2006 survey

Think back to when you **were sick j**ust before you started ARV treatment/**in the past 3 months**: Did you experience the following?		Never	Hardly ever	Some-times	Many Times
1. How often have people avoided touching you because you have HIV?	Were sick	86%	4%	7%	4%
	Past 3 months	94%	4%	1%	0%
2. How often did people treat you badly because you have HIV?	Were sick	84%	7%	5%	3%
	Past 3 months	95%	4%	1%	0%
3. How often did people not eat the food you have prepared or share a meal with you because you have HIV?	Were sick	89%	5%	3%	2%
	Past 3 months	96%	3%	2%	0%
4. How often did people say unkind things to you because you have HIV?	Were sick	72%	7%	14%	5%
	Past 3 months	88%	4%	6%	1%
5. How often did people give you a bad look because you have HIV?	Were sick	74%	6%	14%	6%
	Past 3 months	92%	4%	4%	0%
6. How often were you denied a public service (police, education, etc.) because of your HIV status?	Were sick	96%	4%	0%	0%
	Past 3 months	96%	3%	1%	0%
7. How often did people gossip about you because you have HIV?	Were sick	67%	5%	18%	10%
	Past 3 months	90%	2%	7%	1%

Note: percentages do not always total 100% due to rounding effects

Table 5.11: Who do the respondents report gossiping about them when they were sick prior to starting HAART and in the three months prior to the KSPS 2006 survey?

Did any of the following people gossip about you:	**When you WERE SICK? n=75**		**In the past 3 months n=22**	
	Yes	Who gossiped about you the most	Yes	Who gossiped about you the most
A close family member	16% (12)	11% (8)	18% (4)	21% (4)
Other relatives	29% (22)	6% (4)	14% (3)	
A friend	35% (25)	14% (10)	36% (8)	11% (2)
Your partner (Spouse/Girlfriend/Boyfriend)	12% (8)	3% (2)	14% (3)	5% (1)
A neighbour	70% (50)	30% (21)	50% (11)	26% (5)
Someone in your street	64% (48)	34% (24)	50% (13)	37% (7)
A colleague at work	4% (2)		59% (0)	
Someone from Church/place of worship	3% (2)		9% (2)	
Someone at the clinic	1% (1)		9% (2)	

Note: percentages do not always total 100% due to rounding effects

5.5 Stigma and disclosure

A significant proportion of the KSPS 2006 survey (42%) report disclosing to greater than fifty people (the data is presented in more detail in Chapter 9). These respondents (who had

disclosed to greater than 50 people) were also more likely to report experiencing stigma. Of the 48 respondents who reported that more than fifty people were aware of their HIV status, 66% reported experiencing stigma ($p<0.001$)[33]. In this case, the general experience of stigma was measured by the direct question, 'Have you ever experienced stigma?', which was prefaced by the interviewer reading out the statement: 'Stigma refers to horrible things that people think about, say to or do to you or your family because you have HIV. Stigma also refers to when people stop thinking, saying or doing nice things about/to you or your family because you have HIV'. The analysis described above suggests that disclosure does indeed put people at risk of experiencing stigma. A multivariate analysis follows later in the chapter in order to control for other factors that may affect whether people have experienced stigma other than the size of the disclosure network.

5.6 Keeping one's HIV status a secret and reasons for non-disclosure

Despite the very high levels of disclosure, respondents are not always entirely open with their status and one third report that they would prefer to keep it a secret. As Table 5.12 shows, respondents who report wanting to keep their HIV status a secret also report disclosing to fewer people ($p<0.001$).[34]

Table 5.12: Relationship between disclosure and wanting to keep HIV a secret in KSPS 2006

Number of people aware of HIV status	Odds Ratio	95% CI†
1-5	1.00	
6-10	0.35	0.11 – 1.12
11-20	0.16	0.05 – 0.51
21-50	0.09	0.03 – 0.28
More than 50	0.03	0.01 – 0.09

The data suggest that health-related factors such as bouts of illness or side-effects of HAART dominated other difficulties associated with keeping their HIV status a secret, thus potentially forcing some to disclose. As shown in Table 5.13, over half of respondents reported that it was difficult to conceal signs of illness such as weight-loss, and a similar proportion also reported

[33] By constructing a dummy variable with a value of one if a person has experienced stigma in the past year, a logistic regression showed that respondents who have disclosed to more than 50 people are 80% more likely to report experiencing stigma in the year prior to the 2006 survey.

[34] Using a base of disclosure to one to five people, a logistic regression was run to determine the relationship between a desire to keep HIV a secret and the disclosure radius. Those who have disclosed to 6 – 10 people are 66% less likely to keep their HIV status a secret than those who have disclosed to 1 – 5 people. Those who have disclosed to more than 50 people are 97% less likely to keep their HIV status a secret, and so on. As the number of people disclosed to increases, so does the significance level of the comparison.

that it was difficult to explain bouts of illness. Gossip also featured as a crucial factor associated with the difficulties of keeping HIV a secret. Health-related concerns resulting from the physical manifestations of HIV disease and people gossiping were the most important difficulties, two key influencing factors that will be discussed in greater depth in the qualitative analysis in Chapters 6 and 7.

Table 5.13: Reasons why keeping one's HIV status a secret might be difficult – KSPS 2006

	Do any of the following make it difficult for you to keep your HIV status a secret? (Responses from 73 respondents)			**Most significant difficulty**	
		n	%	n	%
1	It is difficult to take my ARV medication without others noticing	23	32%	4	8%
2	Storing the ARV medicines	30	41%	9	17%
3	It is difficult to conceal the physical signs of my illness, e.g. loss of weight	39	53%	14	27%
4	It is difficult to explain bouts of illness, i.e. being hospitalised, bedridden, or the ambulance arriving at my house	38	52%	13	25%
5	People gossiping	31	43%	11	21%
6	Going to the clinic	2	3%	1	2%

Note: Percentages do not always total 100% due to rounding effects

Considering that many people make a concerted attempt to maintain their HIV status a secret, it is important to understand why this is so, and if they do decide to disclose, what may be the barriers. Respondents were asked to rate the importance of eight potential hindrances to disclosure in general. The survey posed the question: "*Think of the people you have not disclosed to. How important were the following reasons?*" Nine barriers were listed and the respondent rated each barrier on an ordinal scale from 'not important' to 'extremely important' (see Table 5.12). As shown in Table 5.14, fears that the person would stop having sex with them (if the person was their partner) was rated the least important, closely followed by losing friends and losing support. Concerns about whether they would tell other people and not knowing how to talk to others about their status were rated as most important reasons for non-disclosure. The lack of importance placed on losing friends and support likely indicates that respondents are very selective (as indicated in Chapters 6, 7 and 9) about who they are disclosing to in order to garner required support (e.g. family members) while minimising risk, in addition to the fact that disclosure to one's family members has little to do with friendship. The importance of fearing third-party disclosure (or gossip) ties into findings throughout the

quantitative and qualitative analyses and once again reinforces the phenomenon of 'gossip' as likely the most salient perceived and experienced form of stigma amongst PLWH in Khayelitsha. Chapter 6, 7 and 8 take these issues up in greater detail using qualitative methods.

Table 5.14: General reasons for non-disclosure

Think of the people you **have not** disclosed to: How important were the following reasons? (1 - not important <> 5 - extremely important)						
	Not Important	Slightly Important	Important	Very Important	Extremely Important	Mean
You thought they would tell other people without your permission	58% (130)	5% (10)	16% (35)	13% (30)	8% (18)	2.09
You felt too ashamed to tell them	58% (129)	11% (25)	13% (29)	15% (34)	3% (6)	1.93
You didn't know how to talk to them about it	49% (108)	15% (34)	19% (42)	13% (29)	4% (9)	2.09
You thought they would not understand	50% (111)	15% (33)	20% (44)	12% (27)	4% (8)	2.04
You thought they would worry too much about you	54% (120)	14% (30)	12% (27)	18% (39)	3% (7)	2.02
You thought they would stop being friendly	76% (169)	6% (14)	7% (15)	5% (11)	6% (14)	1.62
If the person was your partner, you thought they would stop having sex with you.	72% (160)	8% (18)	9% (21)	7% (16)	4% (8)	1.59
You thought they would stop supporting you	71% (158)	8% (18)	12% (26)	6% (14)	3% (7)	1.62

Note: Percentages do not always total 100% due to rounding effects

5.7 Determinants of experienced stigma

The analysis in Section 5.5 showed that people who report ever experiencing stigma are also more likely to have disclosed to significant numbers of people. However, many factors may influence the experience of stigma other than one's disclosure network. The aim of the multivariate analysis below is to explore whether other important factors in the lives of PLWH are influencing whether they have experienced stigma. Table 5.16 lists the variables that were included in the regression analysis. The analysis includes three regression models (see Table 5.15). The dependant variable in Model 1 is the dummy variable as described in section 5.5 above. The variable takes the value of one if the respondent reports ever experiencing stigma.

Models 2 and 3 are Ordinary Least Squares (OLS) regressions using the Experience Stigma Scale as described in Table 5.3 and Figure 5.1 above.

Table 5.15: Regression Models – Dependant Variables

	Dependant Variable	**Type of variable**	**Regression Type**
Model 1	Ever Experienced Stigma	Dummy/Categorical	Logistic
Model 2	Experience Stigma Scale 2004/5	Continuous	Ordinary Least Squares (OLS)
Model 3	Experience Stigma Scale 2006	Continuous	Ordinary Least Squares (OLS)

Table 5.16: Variables used to assess potential determinants of experienced stigma

1	Age
2	Gender
3	Public Disclosure (>50 people are aware of respondent's HIV status)
4	Months since diagnosis
5	Recipient of a disability grant
6	Wage or self-employment
7	Social support index
8	Did respondent have sex in the past year?
9	Did respondent report poor health at the time of the survey?
10	Did respondent experience physical signs of their HIV such as side-effects?

The variables in the multivariate analysis include both demographic variables and HIV-specific variables. Age and gender were included as it is hypothesised that younger women are more likely to experience stigma than both older women and men in general. Older respondents may also be more likely to garner more respect in the Xhosa culture than younger respondents and therefore less likely to experience stigma. Being a recipient of a disability grant and being wage or self-employed is also included in the analysis. These variables are controlling for two separate effects. Firstly, as a result of the potential loss of an income due to the debilitating effects of HIV illness, PLWH might be blamed for the poor economic status of the household. However, if the person is a recipient of a disability grant or is either wage or self-employed they may have been seen as a significant contributor to household income and therefore their HIV status is either not seen as a problem or in some cases may be beneficial to the household.

The analysis also includes the number of months since diagnosis. Because the dependant variable in Model 1 is based on the question 'Have you ever experienced stigma?', experiences of stigma may be a function of the length of time the respondent has known their HIV status by

increasing the likelihood of experiencing stigma over a long period of time. As the bivariate analysis above suggests, being sick and/or having physical signs that may be signifiers of HIV diseases such as side-effects of HAART or general physical manifestations of HIV disease, are often related to experiences of stigma. These two variables are therefore included in the models.

Having sex in the past year is also included as a proxy for whether the respondent has a sexual partner. In a study of HIV-positive pregnant women in South Africa, Makin et al (2008) found that being married was associated with higher levels of disclosure. The qualitative analysis that follows in Chapters 6, 7 and 8 also show that women consistently have problems with men in their lives, including brothers/fathers and sexual partners. Including a variable which proxies for having a sexual partner may therefore control the potential dominance of sexual relationships as the site within which a significant amount of stigma may occur.

Lastly, the regression includes a Social Support Index as a measure of social support experienced by and available to the respondent. Research in multiple contexts has shown that PLWH who feel supported by others are less likely to feel stigmatized and more likely to disclose (Sethosa and Peltzer 2005; Kalichman et al 2003; Kimberly and Serovich 1996). The Social Support Index was made up of nine items, and included both material support (e.g. 'somebody to take you to the doctor if you needed it') and psychological support (e.g. 'somebody to share your most private worries and fears with').[35] The items were summed to get an overall score with a score of 45 indicating extremely high levels of social support and zero indicating no social support (mean = 36.5; median = 36). Using Cronbach's Alpha as a measure to test the consistency in the responses to the items that make up the index, we were able to see that the scale was reliable (α =0.92).

[35] The Social Support Index includes selected questions from the Medical Outcomes Survey http://www.rand.org/health/surveys/mos.descrip.html. These same questions were also used in the Virginia Commonwealth University and Rhodes University Eastern Cape Pilot Survey.

Table 5.17: Items used to build Social Support Index

	How often is the following kind of support available to you? (0 = none of the time - 5 = all of the time)
1	Someone who will listen to you when you need to talk
2	Someone to share your most private worries and fears with
3	Someone who understands your problems
4	Someone to help you if you were confined to bed
5	Someone to take you to the doctor if you needed it
6	Someone to prepare your meals if you were unable to do it yourself
7	Someone to help with daily chores if you were sick
8	Someone who shows you love and affection
9	Someone to have a good time with

5.7.1 Regression results

Table 5.18 displays the regression results for the three stigma models. The number of observations included in the model (n= 167 - 172) is fewer than the total number of respondents in the survey (n = 224). This is due to the inclusion of the variable measuring months since diagnosis, with many respondents able to recall the year of diagnosis but not the month. However, the models were run again excluding this variable without any change to neither the significance nor the direction of the odds ratios and coefficients.

In Model 1, that explores the determinants of whether the respondents had ever experienced stigma, three factors have a significant effect. Firstly, age was a significant predictor with older respondents having lower odds of reporting that they had ever experienced stigma. The size of the disclosure network, as defined by whether the respondent reported that more than 50 people were aware of their HIV status was also a strong predictor of experienced stigma. This finding, using multivariate methods, upholds the finding in the bivariate analysis earlier in the chapter that showed that people who have disclosed more widely are more likely to have experienced stigma. Lastly, the model indicates that higher levels of social support available to respondents, as measured by the Social Support Index, are less likely to report ever experiencing stigma. Interestingly, neither gender nor any of the health-related factors had an effect on experienced stigma.

Models 2 and 3 show some differences in the determinants of experienced stigma in the two survey waves. As mentioned previously, we cannot make definitive conclusions about changes over time as the phrasing of the questions were different i.e. in 2004/5 the survey asked about all previous experiences of stigma, while in 2006 the survey asked about experiences of stigma in the past year.

In Model 2 (for the Experience Stigma Scale pre-2004/5), two variables showed statistical significance. Respondents that report physical signs of HIV were likely to score 1.89 units higher on the Experience Stigma Scale. Similarly, respondents who reported poor health at the time of the survey were more likely to score almost 3 units higher on the Experience Stigma Scale than those who reported being in better health. The outcomes of Model 2 show that health status seemed to dominate other potential determinants of experienced stigma. This finding agrees with the analysis above, where a much higher proportion of respondents reported experiencing stigma when they were sick.

The determinants of experienced stigma as shown in Model 3 (for 2006) include both health-related and other variables as being significant. Firstly, younger respondents score lower on the Experience Stigma Scale, or in other words, for every one year increase in age, there is a 0.15 decrease on the scale. The model also shows that respondents who have known their status for longer are more likely to report experiencing more stigma in the year between the surveys. Lastly, respondents who report experiencing physical signs of HIV (e.g. side-effects of HAART) also score higher on the Experience Stigma Scale.

Table 5.18: Multivariate regressions to test for determinants of experienced stigma

	Model 1 Logistic Regression		Model 2 – OLS Regression		Model 3 – OLS Regression	
Dependant Variable	**Ever experienced stigma 2006**		**Experienced Stigma Index 2004/5**		**Experienced Stigma Index 2006**	
N=172	Odds Ratio	95% CI†	Coefficient	95% CI†	Coefficient	95% CI†
Age	0.92**	0.85 - 0.99	-0.03	-0.12 – 0.07	-0.15**	-0.29 - -0.01
Female	0.64	0.21 - 1.97	-0.18	-1.89 – 1.53	-0.26	-2.60 – 2.09
Disclosed to > 50 people	2.80**	1.2 - 6.49			-0.03	-1.81 – 1.74
Disability Grant Recipient	0.65	0.28 - 1.50	-1.04	-2.43 – 0.35	0.21	-1.50 – 1.93
Wage or self employed	1.58	0.68 - 3.69	0.15	-1.17 – 1.46	-0.69	-2.48 – 1.11
Months since diagnosis	1.01	0.99 - 1.02	0.01	-0.02 – 0.03	0.04**	0.01 – 0.08
Social support index	0.91***	0.85 - 0.97	0.04	-0.04 – 0.13	-0.07	-0.20 – 0.07
Had sex in the past year	1.02	0.30 - 4.42	-0.92	-2.72 – 0.88	0.49	-1.87 – 2.85
Physical signs of HIV	1.34	0.57 - 3.15	1.89***	0.66 – 3.12	2.19**	0.41 – 3.99
Poor health	1.71	0.48 - 6.10	2.95***	1.19 – 4.71	1.48	-1.30 – 4.26
Constant			17.23***	11.59 – 22.88	18.17***	9.48 – 26.87
† - CI – Confidence Interval; * significance at 10%; ** significance at 5%; *** significance at 1%	Observations	172	Observations	167	Observations	172
	LR chi2(12)	25.84	Prob > F	0.0015	Prob > F	0.0165
	Prob > chi2	0.004	R-squared	0.1536	R-squared	0.1234
	Pseudo R2	0.1423	Adj R-squared	0.1051	Adj R-squared	0.069
	Log likelihood	-77.91	Root MSE	3.9294	Root MSE	5.4835

5.8 Discussion

The main purpose of the analysis in this chapter is to contextualise the more detailed and in-depth qualitative analysis of disclosure amongst the group a HIV-positive activist women that follows in the next three chapters. It does this by using the KSPS survey data from 2004/5 and 2006 to explore the experiences of stigma and the constraints to disclosure amongst a sample of PLWH who have been on HAART for more than one year in Khayelitsha. There are a number of key findings that emerge from both the bivariate and multivariate analyses that are important findings themselves, but also contribute to a greater understanding of the qualitative chapters that follow.

The data shows very high levels of disclosure in Khayelitsha, with 100% of respondents disclosing to more than one person and over 40% reporting that more than 50 people are aware of their HIV status. This finding may be the first to measure such high levels of disclosure in South Africa and is comparable to the high levels of disclosure (81%) found by Makin et al (2008) amongst HIV-positive pregnant women in Soweto. However, the evidence suggests that even though experiences of stigma seem to have diminished over time, the negative consequences of being identified as HIV-positive continue to affect the lives of PLWH in Khayelitsha, with a significant majority reporting less stigma but a small minority reporting more stigma. In particular, being gossiped about by neighbours and in the community is the prevailing form of experienced stigma reported in the survey and is statistically more likely to be a problem faced by women compared to men. Chapters 6 and 7 discuss this particular issue in more detail.

The chapter also explored the relationship between health and the physical manifestation of HIV and experiences of stigma. In almost all cases where respondents were asked about experiences of stigma before starting HAART (when they were sick and likely had visible signs of illness) and in the months preceding the survey, respondents reported a decrease in negative experiences. Starting HAART likely had both profound physical and psychological effects on respondent's lives. Both the qualitative analysis in Chapters 7 and the data shown above (Table 5.11) suggest that visible signs of HIV disease act as a signifier of HIV infection and therefore act as a proxy for disclosure. However, even though respondents were asked specifically about experiences of stigma when they were sick, the social context between 2000 and 2003, when the majority began HAART was quite different to that in 2006 when access to HIV treatment and care in Khayelitsha was more the rule rather than an exception. The data

also suggests that respondents' physiological health had improved with fewer reporting internalised stigma in the year preceding the 2006 survey compared to pre-2004/5. It is important to note however that in the multivariate analysis, the variables measuring health suggested that there was an increased likelihood of experiencing stigma if one has physical signs of HIV or reported poor health however these were not shown to be significant when controlling for other factors.

The multivariate analysis of experienced stigma suggests that having a social support network may mitigate the potential for experiencing stigma, even when PLWH may be exposed to stigma due to the large numbers of people being aware of their HIV status. We do not know where and from whom respondents receive their social support because this was not asked in the survey, but suffice to say that this data indicates that intervention strategies to prevent stigma need to include ways of providing PLWH with both psychological and social support. It is important to point out however that the relationship between social support and experienced stigma was only found in one of the models referring to the 2006 data. This is interesting as one would expect social support to be more important earlier on in one's HIV trajectory. However, this may also indicate that as one discloses more widely and the risk of stigma increases, the need for and importance of social support also increases. The regression results also reinforced the finding that the size of one's disclosure network is related to their experience of stigma. This is an important finding as it points to the obvious risk AIDS activists take when they disclose publicly in their communities. It also ties into principle of boundary turbulence put forward by the Communication Privacy Management (CPM) approach (Petronio 2002; Greene et al 2003). For most PLWH, disclosure is an interpersonal experience and disclosure recipients most often include close family or household members. The response to their disclosure is most often positive as will be showed in both the qualitative and quantitative analysis in the chapters that follow. However, as people disclosure more widely they likely lose control over who has access to their 'secret' and therefore have limited choices over how to manage the potential negative consequences of being know as HIV-positive. These findings tie into the findings in Chapter 6 where the narratives of public disclosure of a group of HIV-positive activist women highlight the challenges they face in avoiding the risks of being stigmatised resulting from public disclosure while still wanting to make a contribution to the struggle for antiretrovirals for PLWH in South Africa.

Chapter 6: The *LongLife* AIDS-Advocacy intervention: an exploration into public disclosure

This chapter explores the issue of public disclosure of HIV status by considering the experiences of the participants in one of the earliest AIDS treatment advocacy interventions in South Africa. This was the *LongLife* AIDS-art advocacy intervention which operated in the early 2000s as part of an advocacy initiative spear-headed by MSF and ASRU to support the AIDS treatment agenda in close collaboration with TAC. The idea was that by publicising the life narratives and art of a group of HIV positive people (all but one of whom was female) that this would contribute to greater public and political acceptance of the need for a national HAART rollout. My research draws on in-depth interviews and participant observation (in support groups, workshops and bodymap presentations) with these eleven HIV-positive African women (who also called themselves the 'Bambanani Women's Group') who were central to the intervention. This chapter reflects critically on the intervention, pointing to the way that so-called 'public' disclosure is far from universal (in that it comprises different audiences in different geographical areas) and that those who disclose their status in one public space often attempt to prevent such disclosure from leaking into their own communities where they would be at risk (as demonstrated in Chapter 5). Despite these carefully constructed public disclosure strategies, some individuals experienced negative consequences as a result of public disclosure. Similarly, Colvin and Robins (2009) note that TAC's emphasis on public disclosure has also resulted in violence against TAC members.

The literature shows that the period immediately after HIV diagnosis is signified by the HIV-positive person having to confront the knowledge that HIV is a life-threatening and stigmatised disease (Brandt 2007; Alonzo and Reynolds 1995). This, in turn has implications for how the individual confronts the issue of disclosure – whether he or she should reveal his or her HIV status or not, to whom, and for what purpose. As noted earlier in the literature review, disclosure of HIV status is understandably a very difficult and complex decision, is made for a variety of reasons and is context-specific (Bharat and Aggleton 1999; Petronio 2002, Greene et al 2003, Chandra et al 2003; Serovich et al 1998; Petrak et al 2001). In essence, the disclosure process is mediated by the individual's level of social support, his or her social standing (such as gender), his or her mental health status, time since diagnosis, the availability of treatment and care (including HAART and/or PMTCT) as well as many other factors. Disclosure

decisions are most often motivated by the need to access medical, financial, material, emotional, spiritual or social support. At the same time, disclosure can serve a psychological function through alleviating stress and helping individuals cope with their HIV positive diagnosis (Schmidt and Goggin 2002; Kalichman et al 2003; Mayfield et al 2008). However, accessing this support may come at a cost with potential exposure to stigmatising attitudes, ideas, beliefs and actions. For example, Varga and Brookes (2008), in their research in Limpopo Province in South Africa, found that young women would go to extreme lengths to avoid disclosing their status to healthcare workers providing prenatal care, even if this meant not accessing antiretrovirals.

In the case of public disclosure, rather different motivations are evident (Paxton 2002) and the costs of disclosure exacerbated (Muula & Mfutso-Bengo 2005). The rationale for public disclosure in general is similar to that of the *LongLife* AIDS-art advocacy intervention. Public disclosure is seen to contribute to a public health agenda in numerous ways. From an advocacy perspective, public disclosure puts a so-called 'human face' on the AIDS statistics, while from prevention perspective public disclosure increases the visibility and proximity to HIV/AIDS and hence hopefully encourages more awareness of, and openness, around HIV/AIDS – a strategy adopted by TAC as evidenced by the widely used 'HIV-POSITIVE' T-shirt (Colvin & Robins 2009).

Figure 6.1 Nelson Mandela and Zachie Achmat wearing the iconic 'HIV-POSITIVE' T-shirt (TAC 2010)

Paxton (2002:563) found in her study of 75 HIV-positive public-speakers in 20 countries that public disclosure probably helps reduce stigma and discrimination though 'breaking through the barrier of silence' around the disease, in addition to having cathartic effects on the person disclosing through confronting stigma. Paxton has termed this the 'paradox of public disclosure' where the people take on potentially significant risks disclosing publicly for the benefit of others, while at the same time experience personal benefits through the cathartic process of disclosure.

Openness around HIV/AIDS hopefully leads to individual and social benefits, including: increased uptake of HIV testing, better reproductive decision-making and safer sex between sexual partners, increased uptake of HAART and PMTCT, and a decrease in levels of stigmatisation and discrimination. In their research in South Africa, Ijumba et al (2004) found that knowing someone with HIV was associated with condom-use at last sexual encounter and negatively associated with multiple and casual sexual partners. As far back as 1991, Gebert et al found that knowing somebody with HIV was associated with increased tolerance of PLWH (ibid.). Despite these and other studies showing a reduction of stigma as a result of increased knowledge and awareness of PLWH, other studies have shown that stigma has increased over time despite increased access to HAART and increased knowledge of PLWH demonstrating once again the complexity of the social context of AIDS (see e.g. Maughan-Brown 2010; Makoae et al 2009).

In the case of the *LongLife* AIDS-art intervention, participants believed (and were encouraged to believe) that by telling "their stories" publicly, they would be supporting prevention, education, treatment and care efforts as described above. However, the private cost of public disclosure is increased vulnerability to stigmatising attitudes, as they are not just dealing with the potential repercussions from significant others, but the wider community too (Muula & Mfutso-Bengo 2005).

This chapter examines the under-researched issue of public disclosure and its relationship to personal lived experience. The chapter first provides a brief history of the policy widely known as GIPA – Greater Involvement of People with HIV/AIDS – as it was this central idea which under-pinned the design of the *LongLife* project. The chapter then documents the disclosure experiences of the women when they disclosed their HIV status publicly. The analysis looks at the dynamics of the interpretation of the word 'public' and in the case of the group interviewed, the notion of 'community' as is used in the often quoted phrase - 'disclosure in the

community'. Using elements from both stigma theory and communication privacy management theory (CPM), the chapter aims to unpack the group's attitudes towards and experiences of public disclosure in order to understand the GIPA policy that is usually taken at face value without considering the potentially serious individual and social difficulties associated with public disclosure as was found in Chapter 5.

6.1 HIV/AIDS stigma and public disclosure

The South African AIDS-stigma literature often cites anecdotal accounts of people who have disclosed their HIV-positive status publicly and then experienced some form of HIV/AIDS stigma as a result. These stories are especially relevant for this research as they are stories about disclosure and thus shape what PLWH expect might happen to them. People choosing to disclose publicly have to consider not only the potential risks in their personal lives such as rejection or ostracism, but also possibly fatal consequences. Anecdotes and rumours about horrific consequences for people disclosing their HIV status inevitably shape perceptions of risk, especially when they are broadcast through the media. As Joffe argues, people are not necessarily aware of threats until they have been brought to their attention, and the mass media is usually the bearer of bad rather than good news (Joffe 1999: 2). The role of the media is therefore a key component in heightening risk (perceived and actual) around disclosure.

The most prominent (and most frequently cited) of the AIDS-stigma stories are: Gugu Dlamini who was stoned to death after disclosing publicly (*Sunday Times* South Africa, December 27, 1998), Nkosi Johnson who was not allowed to attend a specific school (*Mail & Guardian*, June 2, 2001), Lorna Mlofane who was gang-raped and then murdered when she disclosed her status to her attackers (*Mail & Guardian*, February 16, 2006), and Mpho Motloung who was murdered with her family by her husband who then placed a sign on her that read "HIV Positive AIDS" (Geffen 2000)[36]. These highly publicised stories speak to some of the very negative social contexts faced by PLWH in South Africa. Even though many people infected with HIV live in supportive environments, such stories are likely to instil fear in people when they are diagnosed with HIV.

An account of the risks involved in public disclosure is evident in the case of NM & Others vs Charlene Smith, Patricia De Lille, and New Africa Books Ltd which was tried first in the South African High Court and then again in the Constitutional Court of South Africa. In 1999 three

[36] http://www.tac.org.za/Documents/Statements/pr000823.txt

HIV-positive women from an informal settlement near Atteridgeville, Pretoria, were involved in an antiretroviral drug trial through the University of Pretoria. Some time into the trial, participants voiced their concerns over side-effects, fatalities and the apparent lack of concern shown by the project's Principle Investigator, leading to a commission of enquiry. Patricia de Lille, a South African parliamentarian became involved and helped publicize the case, and her actions in this case were also described in her biography commissioned to Charlene Smith (a journalist) and published by New Africa Books Ltd. The case brought against De Lille, Smith and New Africa Books is based on De Lille's biography that included a description of the commission of enquiry in which the names of the three HIV-positive drug-trial participants were disclosed without prior consent (or mistakenly assuming consent). According to the court judgment, the public disclosure of the women's HIV-positive status caused "a violation by the respondents [De Lille et al] of their rights to privacy, dignity and psychological integrity arising from the publication in the book of their names and HIV status without their express authority and consent" (ConCourt 2007:10, brackets added). The Constitutional Courts judges ruled in favour of the complainants and the complainants were awarded ZAR 35,000 (USD 4,960) each, a private apology from the respondents and their names were removed from all future book prints. A passage from the Constitutional Court ruling highlights the crucial legal aspects of HIV-disclosure and PLWH rights to privacy as enshrined in the South African Constitution. Judge Madala argued:

> "The disclosure of an individual's HIV status, particularly within the South African context, deserves protection against indiscriminate disclosure due to the nature and negative social context the disease has as well as the potential intolerance and discrimination that result from its disclosure. The affirmation of secure privacy rights within our Constitution may encourage individuals to seek treatment and divulge information encouraging disclosure of HIV, which has previously been hindered by fear of ostracism and stigmatisation. The need for recognised autonomy and respect for private medical information may also result in the improvement of public health policies on HIV/AIDS" (ConCourt 2007: 17 - Section 42).

The ruling further argues for HIV/AIDS exceptionalism due to the particular ramifications of disclosure by people other than the PLWH.[37]

[37] It is important to note here that human rights activists would certainly question such a position of exceptionalisation of HIV/AIDS. They might argue that all health conditions should be treated with as much confidentiality and care as HIV/AIDS. This particular debate has proven to be divisive between human rights activists and public-health practitioners.

> There are in the case of HIV/AIDS special circumstances which justify the protection of confidentiality bearing in mind that the disclosure of the condition has serious personal and social consequences for the sufferer. For example, such a person stands to be isolated and even rejected by others. In the present case, each of the applicants testified as to the several setbacks which occurred in their lives following the disclosure of their status. The first applicant had her shack burned down by her boyfriend who has since left her and broken off that relationship. The second applicant has withdrawn from society for fear of being ostracised by her family. The third applicant has shied away and has not told members of her family about her condition which depresses her. (ConCourt 2007: 25 - Section 63)

Even though the judgement does not refer to any particular academic literature on the nature of stigma in South African society, it nevertheless reflects a general acceptance that PLWH face a highly stigmatised environment and thus should be compensated if their privacy is breached in the public domain and thus put at risk of stigmatising behaviour. And as the multivariate analysis in Chapter 5 showed, experiences of stigma are indeed statistically related to the numbers of people that are aware of one's HIV status.

6.2 Why is public disclosure deemed desirable?

Given the risks facing PLWH, why is public disclosure deemed desirable by advocacy projects such as *LongLife*? The answer lies in the widespread acceptance within the international AIDS policy arena that there needs to be a greater involvement of people living with or affected by HIV/AIDS (GIPA) in both the protection of the rights of individuals with HIV/AIDS and their own struggle for treatment, care and support (see e.g. UNAIDS 1999). Even after the death of Gugu Dlamini, AIDS activists continued to campaign for public disclosure:

> "We will lobby and advocate to ensure that the human rights and dignity of PLWH/AIDS are upheld in all spheres. We will encourage and support PLWH and AIDS to disclose their status and to make the epidemic more visible and more real" (NAPWA 1998)[38]

[38] http://www.info.gov.za/speeches/1998/990428438p1006.htm

GIPA is a concept that refers to the recognition that people infected or affected by HIV/AIDS make important contributions by shaping the response to the epidemic, and involves creating a space in society for their participation in all spheres of that response (*ibid.*). The beginnings of GIPA can be traced back to the Denver Principles of 1983 and then formalised in the Paris Declaration of 1994 issued after the Paris AIDS Summit and agreed upon by the 42 attending heads of state or their representatives.[39] Amongst many other relevant paragraphs, the Paris Declaration of 1994 states:

> "Support a greater involvement of PLWH/AIDS through an initiative to strengthen the capacity and coordination of networks of PLWH/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments."

The GIPA concept was expanded upon in the Report of the Strategic Meeting on Prevention (HIV and STDs) in Geneva in October 1994.

> "Through their commitment during the past decade, based on their unique life experience, PLWH/AIDS and their networks and organizations have given a human face to HIV/AIDS. By taking an active part in prevention they help safeguard the principle of non-exclusion in these programmes, increasing their effectiveness. And because they share the same values as their communities of origin, they have special credibility in helping create a favourable climate for attitudinal and behavioural changes. As more PWAs (sic) have become involved in prevention, their visibility has encouraged others living with the virus to be open about their infection status, making it possible for them in turn to contribute openly to prevention, care and support programmes."

In terms of public disclosure, the quoted paragraph above emphasizes the importance of the PLWH's openness or visibility that encourages others to be open with their HIV status and hence contribute to wider prevention and support goals.[40] The Paris Declaration was a bold step taken by the global AIDS community in order to transform global efforts to mitigate the impact of HIV/AIDS and limit the spread of the epidemic. From a South African perspective, the

[39] http://www.ecpp.co.uk/parisdeclaration.htm accessed 11 July 2007.
[40] It is notable that access to ARV treatment did not feature as a goal of GIPA in 1994.

realisation of the Paris Declaration and similar initiatives materialised with the establishment of the TAC in late 1998.

However, as discussed previously, public disclosure is a complex and difficult process for the individual disclosing. This was further highlighted by the public disclosure of Justice Edwin Cameron, a homosexual high court judge in South Africa. His disclosure of his positive HIV-status was notable in the history of HIV/AIDS in South Africa as it was the first time that a public official holding such a prominent social stature had been open about his or her status. The following text is taken from a press statement published by TAC after Judge Cameron's disclosure.

> Justice Cameron's openness is a courageous personal step. It has been taken after careful consideration of the impact that it will have on his personal life -- as well as on the lives of other PLWH and AIDS. We call on all South Africans to continue to respect his right to privacy as well as the rights of millions of others. We restate that the decision to be open about one's HIV status is voluntary. It should be made only when a person feels safe in the knowledge that such disclosure will not lead to personal abuse, unfair discrimination and stigma. (AIDS Consortium, AIDS Law Project, Centre for Applied Legal Studies, National Coalition for Gay and Lesbian Equality, and the National Association of PLWH/AIDS – Treatment Action Campaign, April, 1999 http://www.tac.org.za/justice.html)

Judge Cameron's described the decision-making process in his book *Witness to AIDS* (2005). He describes in detail how difficult it was for him to disclose – despite the fact that he had a high income, permanent employment as a high court judge, medical insurance and enjoyed the guaranteed support from friends and family. He attributes the difficulties of disclosing to the shame he felt for being HIV-positive. Because of his stature in South African society, the kinds of negative consequences experienced by people like Gugu Dlamini were highly unlikely in his case. Nevertheless, his fears highlight the difficulty of public disclosure and the multiple forms of AIDS stigma (including perceived, experienced and internalised) experienced by diverse people in South African society. Returning to Paxton's 'paradox' where in facing AIDS-stigma through disclosure, one finds psychological release and liberation from the burden of secrecy, Cameron and others who publicly disclose realise the potential social benefits of their actions despite the potential negative consequences. The implication is that if public disclosure by the rare few results in more people disclosing their status to others and an increased perception that

HIV is a chronic and manageable illness affecting all people, more progress on the GIPA agenda will be achieved in addition to greater visibility of the AIDS epidemic.

6.3 Methodology

The data used in this chapter is largely ethnographic insofar that it relates to my experience of working with the women involved in the *LongLife* project between 2003 and 2007, first as a project facilitator and then as a researcher in the *LongLife* AIDS-art outreach project. The women worked as peer-educators and workshop facilitators in this project. The *LongLife* advocacy[41] project culminated in a book, *LongLife: Positive HIV stories* (2003). The book was launched in December 2003 at an exhibition of "bodymaps", the set of 14 life-size body paintings that are the central artistic theme of the book. The bodymaps are life-size body tracings originally used as narrative therapy support tools. In the creation of the bodymaps, workshop participants are led through a series of instructions that encourage them to record their life stories with paint on tracings of their bodies. The process is based on the assumption that the body is a 'museum of one's history', and by using the body as the focus, the process aims to encourage participants to identify stories, emotions, feelings, memories and experiences that are related to a particular area, part or feature of the body.

As is described below, the women have presented their bodymaps at lectures, conferences, on radio, in the print media, universities and exhibitions. The bodymaps have been on exhibition in four continents. I observed these women in multiple contexts; from running support groups, presenting the project and telling their stories to various audiences both within Khayelitsha and a range of other local and international settings, in *Mapping our Lives* and *Memory Box* workshops, and in other qualitative and quantitative research projects. It is through this position that I have been able to observe the effects of the 'HIV/AIDS professional environment' in addition to formal interviews and many informal conversations over the years.

As described in Chapter 4, the in-depth interviews took place at the beginning of 2004 and were supplemented by updated information using self-administered questionnaires, participant observation and numerous informal conversations up to 2006 (see draft interview schedules in Appendix B). The original in-depth interviews were open-ended. Questions included: "What

[41] Advocacy can be defined as "A process to bring about change in the attitudes, practices, policies and laws of influential individuals, groups and institutions, carried out by people proposing improvements on behalf of themselves or others" (Cornu and Attawell 2003:8).

do you feel about public disclosure?" and "Tell me about your experiences of public disclosure?" These general questions aimed to probe the individual's general experiences of disclosure outside the household context but including disclosure in the neighbourhood and in wider community and activist structures. In doing so, I was able to gather disclosure experiences relating to both the private and public domains.

To analyse the qualitative data relevant to the current chapter, I use a combination of thematic analysis, stigma theory and communication privacy management (CPM) theory. As described in Chapter 4, the concept of 'boundary turbulence' within CPM theory occurs when there is a loss of control over who has access to the individual's private information. This resonates strongly with public disclosure because disclosure in the public domain ultimately leads to vulnerability, especially when disclosing to large numbers of people and thus losing control over negotiating and managing the 'secret' with a potential risk that the 'HIV-secret' could reach people who the discloser would have preferred to have managed more carefully.

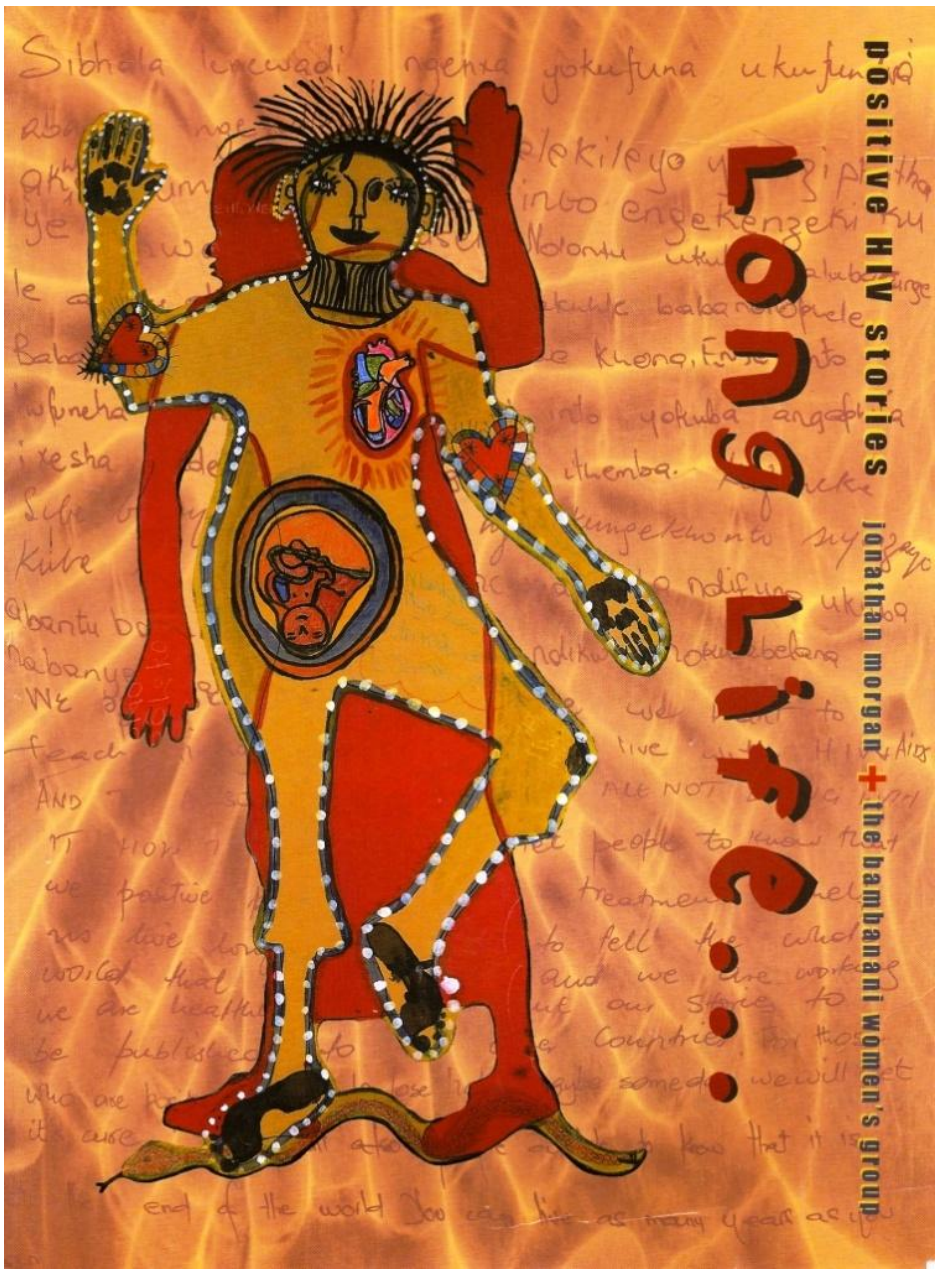
6.4 A history of LongLife: an opportunity for advocacy, research and outreach

From an advocacy perspective, the stories told by the women illustrate the life-changing benefits of HAART adding to the dominant public discourse on HIV/AIDS at the time which focused largely on issues of access, economics and the causality of AIDS. For example, Thembi's experience of starting HAART when she was dying with a CD4 cell count of zero, and her consequent recovery is a hard-hitting way of giving meaning to public advocacy. The life stories told by these women in the form of the book therefore gives a voice to this particular marginalised group, who could be seen as representative of a broader grass-roots constituency needing access to HAART. Through the use of narrative, these women were able to mount some form of resistance to the dominant discourse of the South African government on HAART, particularly that they were unaffordable and possibly undesirable, the view of President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang (see Nattrass 2007 and discussion in Chapter 2).

The process out of which the bodymaps and the book came to be created is important contextual information. As is described in the next section, the women were paid a small stipend to participate in the workshops in which the bodymaps were created and the stories told. The women subsequently worked on ASRU's 'outreach' arm – where their main 'job'

was to educate others, facilitate HIV support groups, present their body maps (which entailed public disclosure), and run body map workshops. In some ways, the stories of these women were commodified with consent of the women as they were clearly benefiting through income from the workshops, the sale of the books and the prints of the bodymaps. At the same time, ASRU and MSF were confident that their 'HIV stories' and their representations through the book and art-making process could make a major contribution to advocacy debates occurring at the time about public access to HAART and PMTCT.

Figure 6.2: The cover of the *LongLife* book



However, a qualitative exploration of the processes underpinning their disclosure experiences paints a more complex picture. This is due to the fact that public disclosure was central to the success of *LongLife* – and public disclosure comes with many risks to the individuals involved. Details of the intervention and risks are described below.

Early in 2001, ASRU facilitated a series of Memory Box workshops in HIV support groups in Khayelitsha. These support groups were coordinated by Red Cross, *Mothers to Mothers-to-Be (or mothers2mothers)*[42] and MSF at the Site C clinic in Khayelitsha. The Memory Box workshops were based on a combination of narrative[43] and art therapy. Workshop participants were taken through a series of exercises through which they made memory books and memory boxes. They were then encouraged to share their life narratives through painting and writing in the memory book, and decorating and preparing their memory box into which they could store valuable objects, photos, messages and historical recollections. Once the books and boxes were completed, the group shared their stories and experiences. These creative products acted as symbolic spaces in which the support-group participants could feel comfortable sharing their life stories and experiences of HIV.

The Memory Box concept was taken from a group of HIV positive mothers in Uganda who used memory boxes and books to disclose their positive status to their families and children. These women were members of the National Community of Women Living with HIV/AIDS in Uganda (NACWOLA) and were at the forefront of mitigating the effects of HIV/AIDS in their country (Witter and Were 2004). The general idea behind the memory box concept is that parents would make 'memory boxes' in order to create a legacy for their children to have once they had died from AIDS. In the boxes, they put stories about the family, traditions and heritage, audio recordings, birth certificates and other sentimental items. Memory work in the Ugandan context (and early on in South Africa) focussed on dealing with loss, bereavement work and succession planning (Ibid.). However, this approach was developed in an environment where wide-spread access to HAART and PMTCT was a fantasy, something that PLWH could not imagine in the foreseeable future. At the time of writing, the context of the

[42] mothers2mothers was founded by Dr. Mitchell Besser in 2001. Besser, a gynecologist working with at-risk pregnant women in California, USA and South Africa, consulted for the clinical roll-out of PMTCT. While working at Groote Schuur Hospital in Cape Town, he realised that even when medical treatment was available to these women, it was often less than effective because of social, emotional and psychological barriers to success. To help break through those barriers, Besser enlisted other new mothers living openly with HIV/AIDS who, as Mentor Mothers, began to connect with and educate their pregnant peers. http://www.m2m.org/about-us/history-a-timeline.html

[43] Narrative therapy was pioneered by Michael White and David Epston. See www.narrativeapproaches.com

HIV pandemic is quite different as HAART is now widely available in the public health sector with over 1.5 million PLWH in South Africa accessing HAART.

After the initial workshops, ASRU selected a group of HIV-positive, Xhosa-speaking African women from the workshops in Khayelitsha and they were trained in Memory Box techniques. The training aimed to empower the women with relevant workshop facilitation and counselling skills. In a broader light, ASRU aimed to make the Memory Box Project participatory on the grounds that prevention, education and support messages hold far more weight when they come from peers (Campbell, 2003; Paxton, 2002). After five months of training, the women began facilitating workshops in support groups for other HIV-positive people principally in various clinics in and around Cape Town that provided access to HAART or PMTCT services. The workshops were funded by the organisations requesting the workshops, and the women were paid for their facilitation services. This was in addition to being paid a monthly stipend while training. ASRU envisaged a group of women living with HIV who would function as role-models for 'positive living', successful PMTCT and HAART, and disclosure within their own communities. Approximately half of the women had already been through the PMTCT programme[44]. The rest of the group were on HAART.

At that time, in 2001/2002, the South African government and the Treatment Action Campaign (TAC) were in the throes of a larger struggle against the multi-national pharmaceutical companies over access to cheaper generic medicines. The pharmaceutical companies subsequently settled out of court.[45] TAC then began fighting *against* the South African government to provide Nevirapine or AZT to pregnant women and rape victims.[46] South Africa was in the midst of intense internal public debate and activism over the provision of ARVs to pregnant women and subsequently also over the provision of HAART to people with AIDS (Nattrass 2007).[47] The government argued that the drugs were toxic and unaffordable. MSF, TAC, ASRU and many other organisations argued that ARVs could save millions of lives,

[44] In 2001, the Western Cape was the only province in South Africa that offered Nevirapine or AZT (mono-therapy) PMTCT to decrease the probability by approximately half of pregnant women transmitting HIV to their newborn babies through vertical transmission.

[45] In March 2001, TAC was accepted as amicus curiae in the case brought by the Pharmaceutical Manufacturers' Association (PMA), initially in 1997, against government legislation allowing for the importation and production of cheap generic equivalents of patented drugs. TAC's intervention turned attention from the broader issue of drug prices to a focus on the cost of patented ARVs. This prompted the government to settle the case, which it did on 19 April 2001. While the settlement allowed government to import cheap generics, the Health Minister told the press afterwards that ARVs were still unaffordable and that the necessary infrastructure was lacking for a HAART rollout (Nattrass 2007).

[46] The judgement can be downloaded at http://pmtct.org.za/docs/mtctjudgement.doc

[47] See also, Nattrass 2001, Nattrass and Skordis 2001, Kuhn 2002, Nattrass 2002, Sparks, 2003.

serve AIDS prevention purposes, and mitigate some of the socio-economic effects of the pandemic (Nattrass 2004). It was seen as an appropriate time for PLWH to be involved in their own struggle for dignity and human rights.

The women, and supported by ASRU, were encouraged to share their stories of PMTCT and HAART with other PLWH. Elements of their stories included: Nonceba's first baby died from AIDS when she was only 16 months old because she was not diagnosed; Buyiswa's two children are both HIV-negative after PMTCT; Thembi was AIDS-sick but went on ARVs and is now healthy and fully employed; Ntombi's son was born HIV-positive (because she did not receive PMTCT) and died in 2004 when he was 8 years old; Sylvia's little boy is HIV-negative thanks to PMTCT. These are a few of the sad and uplifting stories of these women which the women, ASRU and MSF thought were in the public's interest to hear.

From May to July 2002, Jane Solomon, an artist, initiated a body map workshop with the group. The body maps were created over ten morning workshops held at the MSF clinic at the Khayelitsha day hospital in Site B. The participants worked in pairs and traced their bodies onto life-sized sheets of cardboard. (The instructions used in the Bodymapping workshop are detailed in Appendix D; Figure 6.2 is a photo of a bodymap workshop). According to Solomon, "Body Mapping investigates the world of symbols, self-portraits, anatomical diagrams, colour, decoration, beauty, health, emotions, experience and identity" (*LongLife* exhibition abstract, 2003). The women worked as individuals, in pairs and as a group. Sharing, discussion and reflection were integral parts of the workshops. The bodymaps included painted representations of HIV, the 'battle between ARVs and HIV', personal symbols of power, scars, stories, and other areas of emotional and physical significance (Vasquez, 2004, Subotsky, 2004). The bodymaps and memory books acted as tools to elicit narratives of the women's experiences of life and HIV.

In the South African context this group was relatively unique. The vast majority of PLWH in South Africa did not have access to HAART nor PMTCT as the public roll-out only began in early 2004 and was fragmented at best in terms of pace and coverage of those in need. By the end of 2005, it was estimated that total HAART coverage was only 25.2% [20.0 – 55.7] (Nattrass 2007:131).

Figure 6.3 Photo of body mapping workshop at HIV-positive support group in Langa, Cape Town

Figure 6.4: Thembi's finished bodymap

6.5 The multiple meanings of 'public'

The concept of "public" embodies different meanings for different stakeholders involved in the *LongLife* intervention. Each of the women constructed their own meaning of 'public' according to the risks and benefits of disclosing to a particular individual or group. The following sections of the chapter focus on the divergent and convergent constructions of 'public' as described by the women. The breadth of 'public' is evident from the introduction they wrote for the *LongLife* book. Note that Jonathan Morgan (the coordinator of the project and co-author of the book) did minimal editing to ensure that the voice of the women came through as authentically as possible.

> "We **Bambanani women** are making this book because we want to teach PLWH. And to also teach those who are not living with it how to survive. And to let people know that we positive people are getting a treatment to help us live longer. We want to tell the whole world that we are many and we are working. We are healthy. Also we want our stories to be published to the other countries. For those who are positive not to lose hope, maybe someday we will get a cure. We want people outside to know that it is not the end of the world. You can live as many years as you want." (Morgan and the BWG 2003:3)

The notion of 'public' seems to be all inclusive according to this introduction and resonates clearly with the GIPA advocacy and activist discourse and agenda. However the women subscribe not only to an advocacy discourse aimed at groups with more power than themselves – notably the South African government. They also include their HIV-positive peers and the general population who they believe needed to hear their stories in order to be educated about the realities of living with HIV. They aimed to "teach PLWH and to those who are not living with it how to survive." They wanted to "tell the whole world" about their stories through publishing "to the other countries." These are *their* words, but they need to be analysed in terms of the relationship between the *LongLife* project and their private lives.

6.6 Fear and gossip

According to the majority of the women, living with HIV is difficult whether their status is made public or not. In the focus group discussions, the women expressed their fears of

disclosing in their 'community'. These fears were based on a range of experiences that illustrate the connection between their activist and private lives. They felt some pressure to disclose as this was a key element of their role in the project (as outreach workers and members of the ASRU/MSF advocacy initiative) and their identities as activists, yet their own and others' experiences, present a dilemma. The women acknowledge the importance disclosure in the activist sense, but were also highly cognisant of the risk of disclosing in their private lives.

In the focus group discussion, the question was posed: "Why is it difficult to disclose in the community?" Their responses were based on a loose interpretation of 'community' as referring to both large and small numbers of people e.g. support groups, workshops, church gatherings, lectures at universities, groups of friends etc. However, 'community' was most often constructed as the particular 'neighbourhood' in which the respondents lived.

> … It is very hard to disclose in the community because even though she has not told them anything, whenever she passes to her neighbours or somebody like that […] she gets like consciousness, guilty consciousness that maybe they are talking about her. (Zameka translated by Sylvia)

> So I told myself to that area where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can talk bad things outside about you... the feeling of disclosing to the community, you give yourself a lot of stress. Because if you walk, come out of your gate and you walk out in the street, you see the people making some funny jokes. So that thing can hurt you because you disclosed to them now they got stigma on you now. (Sylvia)

> The other reason why it is hard to disclose to the community ….Maybe you will decide to disclose to the neighbours. There are big mamas there that know your mama. They gossip … they are witches; they practice witchcraft and all this things. And you just go and say this, I am HIV positive …. They say bad things and all things like you are sleeping around and all those things, you know. I think the best thing for you to disclose is like to disclose like maybe in a group of people like maybe say five. If they spread it, it is up to them. (Thembi)

The experiences resulting from being identified as HIV positive showed that 'gossip' is the most common and hurtful form of stigmatising behaviour. (This finding is also evident from the quantitative analysis in Chapter 5). In a conversation with Sylvia and Thembi, I asked what 'gossip' meant to them as 'gossip' had been mentioned many times in the interviews. They explained enthusiastically that 'gossip' meant being spoken about behind their backs and being called prostitutes or "loose" women. This, they recognise, is a source of great social danger to them, either from loss of reputation, or worse still, attracting the attentions of those practicing witchcraft and seeking to cause harm through the mobilisation of occult forces.

In addition to being stigmatised by HIV negative people in their communities, Sylvia and Thembi claimed that other HIV positive people also gossip about them. According to these women, other HIV positive people gossip in order to hide their own positive HIV status and therefore defend themselves against gossip. Because the women were employed in ASRU's outreach program, they were "earning money" and "wearing nice clothes," thus resulting, they believed, in others gossiping about them out of jealousy rather than stigma per se. And, as jealousy is believed to be the source of witch-craft attacks (Ashforth 2005), this too suggests sources of danger beyond social unease. (This issue is addressed further in Chapter 7).

Avoiding stigmatising attitudes and behaviour such as gossip, while still being able to contribute to the 'struggle' against the HIV/AIDS epidemic, was integral to the life strategies of the Bambanani women. As mentioned previously, the women pointed out that both they are often identified as 'HIV positive' from their work in support groups (even when they may pose as counsellors). This is an example of 'boundary turbulence' resulting from their professional work and highlights a key contradiction between doing their 'jobs' and managing their private information. Because their job was to be open with their status, and a key part of their role was to disclosure publically, it could be perceived as problematic if they were to request that their status be kept a secret. The women therefore employed strategies that limited possible negative consequences resulting from their public disclosures.

> But I disclose to the other [people] like in Gugulethu, Nyanga, Eastern Cape, those people they don't know me and uh the other day, the exhibition day, I was on the TV, on ETV. But the people didn't realise that I was HIV positive because I was talking [as] the counsellor …. Yes, like a counsellor. (Sylvia)

Sylvia reconciles the fact that she has not disclosed in her neighbourhood by contributing to the struggle against HIV/AIDS in other ways. She uses her knowledge of HIV/AIDS, not only as an HIV positive person but also as an HIV counsellor. By acting as an HIV counsellor (i.e. a neutral professional), she is able to decrease the possibility of gossip and other negative repercussions in her private life, as HIV counsellors are not necessarily HIV positive themselves (but are likely to be in reality). Sylvia is therefore able to devise solutions which promote a carefully chosen identity in a particular situation in order to maximise benefits and minimise risk.

6.7 Creating barriers to identification

The *LongLife* project team was aware that public disclosure involved risks for the Bambanani group, even though the precise nature of that risk varied on an individual level and was very difficult to predict. Attempts were made to ensure that the needs of the different members of the group were met as much as possible. Each person was at different stages of disclosure throughout the project[48]. At the time of the book launch and exhibition, the majority of the women requested that ASRU tape over their surnames on their body maps, or digitally removed the surnames from the prints. Four of the thirteen have first-names and surnames, while nine have only a first name on the prints. Thembi, Buyiswa, Lizeka, Nokwanda and Ntombi did not mind having their surnames in the book or on their bodymaps as they were totally open with their status, and Thobani did not complete his bodymap but said that he would have put his full name if had the chance.

It was of course perfectly acceptable that some of the group members did not want their full names to be made public. Because of the public nature of the project, they did not have total control over who would see the bodymap exhibitions or who would read the book. Covering one's identity could be viewed as symbolic of the social context of HIV, in which the fear of being identified as HIV-positive prevents disclosure. It could also be seen as an attempt to reduce boundary turbulence, although in this regard, the fact that they were often physically present at exhibitions and gave talks about their art work rendered boundary turbulence a distinct possibility, even where names had been blocked out.

[48] There are 14 bodymaps in the *LongLife* exhibition set. Only 13 bodymaps and their corresponding narratives feature in the book as Nokwanda found employment elsewhere while the book was developed.

The fears of disclosure expressed by the women are not exclusively self-interested, but also extend to the potential ramifications of their disclosure to their significant others.

> You know, if they can throw stones on you, you don't worry about that. But I can't disclose to them because I am worried about my family. I did disclose to them and they gave me a support. But I don't want the other people can throw stones to my family… (Sylvia)

By opting for only their first names and in some cases an alias for the book and bodymaps, the women were protecting their identity to some extent. Interestingly, the book and the bodymaps provided incredibly detailed information regarding the individual's life histories, families, dates and places of birth, education etc. If somebody really wanted to discover the owner of the bodymap or narrative, it would be possible.

Interestingly, since the launch of the book and exhibitions, many of the women have opted to take the tape covering their surnames off their bodymaps and reveal their full identity. This is as a result of their disclosure to certain significant others, as in the case of Sylvia who disclosed to her family for the first time in December 2003, four years after her diagnosis, and Nonceba who just felt that it was just time that she did not mind who knew her status (as she had just started HAART).

6.8 Disjuncture between 'partial' and 'full' disclosure

The disjuncture between 'partial' and 'full' disclosure is an issue amongst the group. Although the group was generally pro-disclosure, they were divided according to their individual needs concerning disclosure and living with HIV in general. Buyiswa was particularly opinionated with regards to the connection between access to HAART/PMTCT and disclosure. This is one of the main reasons she was employed to lead the group of women in 2003. At a photographic exhibition by photographer Gideon Mendel at the Oliver Tambo Recreation Hall in Khayelitsha, Buyiswa told Morgan that she did not understand "why the people in the photographs were hiding their faces". She said that they were the lucky ones who were accessing treatment and should therefore showcase the positive life-changing benefits of ARVs to all who denied this at the time.

> …. I hate when people hide, hiding themselves, because they are the ones who are fortunate. Very few people [who are HIV-positive and are on treatment] are getting treatment in Khayelitsha, more especially in Khayelitsha, because of the limited resources from MSF. But at least they are lucky enough to receive medication. So at least they should stand around to be an example to those who … are going to start treatment. Because I think they can be better counsellors for those who are starting treatment. But I don't know how they [the rest of the women and others on treatment] see it… Then say if I was taking for example ARVs, I will say that I am getting ARVs from MSF and I am healthy. They look to me and see that I am healthy; they will know for sure that the treatment is working, unlike what was being said for more than three years, the drugs were toxic. (Buyiswa)

Buyiswa's words resonated with only a small part of the group. Buyiswa and Thembi felt that the majority of PLWH need to move from 'partial' to 'full' disclosure once they gained access to treatment in order to show the life-changing benefits of treatment. Thembi explained to the author and academic Susan Sontag when she visited the project in Khayelitsha in 2006 that HAART "had given her wings to her future," and she is constantly promoting ARVs to PLWH and to those interested in the challenges posed by HIV/AIDS. In 2007, Buyiswa was still not on HAART as her health did not require it, but she had been through PMTCT to protect her un-born child. These two women, specifically Buyiswa, were the strongest activists in the group in terms of their willingness to disclose openly in most public gatherings. Buyiswa's strong activism can be seen through her participation in the TAC's civil disobedience campaign in 2003[49] that aimed to force the South African government to commit to and speed up the roll-out of HAART.

Buyiswa and Thembi were chosen most often to speak about *LongLife* in the different media because of their openness and activist perspectives. Even though some of the other women were not willing to take activism to such levels, the entire group agreed that this type of activism was necessary in the South African context at the time. And all of the women were activists to some extent. They wore MSF and TAC 'HIV-POSTIVE' T-shirts, attended TAC and MSF rallies and meetings, gave presentations about HIV/AIDS, and were all motivated to facilitate workshops in HIV support groups.

[49] In March 2003, TAC launched a civil disobedience campaign that included marches, invasions of police stations and other government buildings and institutions, disruptions of speeches and meetings in which the Minister of Health was present (see detailed description in Nattrass 2007:114)

Looking at to whom the women chose to disclose and their corresponding disclosure strategies is a critical lens through which to understand the conflicts these women faced, particularly in the context of the *LongLife* project. The recipients of their disclosure messages can be seen as the different types of audiences at the numerous presentations, exhibitions, lectures, in their household, at workshops and other gatherings. For example, Sylvia has no problem discussing her HIV status and her life story when talking to audiences from outside South Africa and outside Khayelitsha. She was an excellent facilitator of workshops, she gave numerous lectures at universities and conferences throughout South Africa and disclosed to most of her family in the Eastern Cape. But, during the period of this study she did not disclose to her long-term boyfriend, to certain other members of her household, and she was not prepared to go on South African television. As described in Chapter 7, it was only in December 2003 that she disclosed to most of her family (up until then, she had only disclosed to her sister and brother who was also HIV-positive). Similarly, Buyiswa spoke about her HIV status to many audiences, but had not disclosed to her boyfriend, and she did not feel that it was necessary considering she was using condoms. Others in the group adopted a similar position in that if they were using condoms with a sexual partner, especially a new partner, they did not feel the need to disclose (see more detailed discussion of this in Chapter 8).

6.9 Different media as different publics

The Bambanani Women's Group took part in a range of advocacy activities associated with the *LongLife* project. They presented their bodymaps at exhibitions in Cape Town, Durban, Johannesburg, New York and London; some of the women gave presentations at the *Sex and Secrecy* conference in Johannesburg in 2003, at the *HIVAN Artists Action Around AIDS* workshop, at the *Women, Gender and HIV* conference at UCT, at many university undergraduate and postgraduate lectures, and of course in countless therapeutic workshops in HIV and non-HIV support groups. Radio and print media interview requests were accepted, as the risk of identification is low. According to Dunyiswa:

> I am not worrying because to the radio, but I am worried to go to talk to the TV. Everybody [will] look at me on the TV. But if I am going to talk to the radio I am not worried because those people didn't see me. (Dunyiswa)

This feeling is generally shared by the group. Therefore requests for television appearances in South Africa were usually turned down, in order that the women did not create the opportunity to be recognised publicly. ASRU received many requests from filmmakers wishing to make documentaries on the outreach intervention and the *LongLife* book. If the filmmaker could prove that the audience was exclusively foreign to South Africa, some members agreed to be filmed. This discriminating reaction to the media is consistent with a strategic approach to disclosure adopted by all the women. Such a strategy aims to minimise the risks of disclosure through analysing the negative potential of the diverse audiences. 'Audiences' in this case refers in a similar way to Petronio's (2002) conception of a disclosure 'recipient' and can range from one person to many. According to the women's accounts, recipients are decided upon using the individual's conceptualisations of race, class, social distance, and costs and benefits related to the individuals desire to help others and change the social dynamics of HIV.

> What I was saying is that our community, the black community is different from the white community and the coloured community. We will find it easier to disclose to white people, to a white community. It is easy, you don't feel afraid because those people they won't feel jealousy for you or get you down. They will always pick you up, saying good things about you. You must be strong, you know, those things. As well as coloured community. But if you come to the black community, if the people that know you, gossip and jealousy and like getting you down, you know. They not like giving you support, you understand. So sometimes it is easy to, maybe also if there is mixed, mixture of communities, like white, coloured and black together, that is also easy for you to disclose…. (Thembi)

Thembi specifically refers to race (and related fears about jealousy and witchcraft) as a factor influencing the disclosure choice, although it may well be that social distance is also a crucial determinant. Similarly, Sylvia stated previously that she did not mind disclosing in Nyanga, Gugulethu and Masiphumelele which are predominantly black areas. In a similar study of in Masiphumelele[50], respondents viewed Khayelitsha as a place of support and openness, where disclosure was easy and common-place (Kahn 2004). The interviews show quite clearly that 'public' disclosure can happen in any community – as long as it is not their own community and that the boundaries between these different communities are sufficiently rigid that boundary turbulence is unlikely. Their confidence that nobody in their community would be present in audiences in other communities speaks to the history of residential segregation under

[50] Masiphumelele is an urban, informal settlement on the outskirts of Cape Town.

apartheid – a legacy which continues to this day in the form of continuing class and race-based living patterns (see description of Cape Town and Khayelitsha in Chapter 4).

6.10 Disclosure as a performance: the professional, AIDS-advocate and activist

The successful marketing and promotion of the project as a research, outreach and advocacy intervention (which also included the sale of limited edition numbered prints, the sale of the book and a website) relied on the type of 'anonymous' or 'partial' disclosure discussed previously. Most of the participants were only 'partially' public with their HIV status. The project team was of the view that 'partial' disclosure, within the context of a sympathetic and relatively safe environment, was empowering to the women involved, and moreover, that putting a human face (in the form of artworks and narratives) to this pandemic would be of value to achieve the desired advocacy objectives. In a letter to the group from Dr Herman Reuter on the death of one of the members of the group, he said:

> 'I think that in many ways this book provides a better reflection of the impact of HIV on South Africa than most statistics do. This book is about the lives of just a few South Africans. But that is what HIV is all about. It's about lives and valuing them all. We hope that our positive experience of using ARVs in Khayelitsha will help the case of the Treatment Action Campaign. We hope that our government realises it has the capacity to deal with the HIV crisis.' (Morgan and the BWG 2003: 71).

The bodymaps and the *LongLife* book potentially provided this group of HIV-positive women with a safe way to present themselves publicly thereby fulfilling both their needs to educate others and stand as role models to their peers, in addition to concretising ASRU's advocacy ambitions in support of universal access to HIV care and treatment. However, as has been described above, and with more analysis below, the perceived safety hiding behind one's body map and a pseudonym was actually far more complex and difficult for the people disclosing.

The women succeeded in presenting and at times marketing themselves as activists, but equally importantly, as counsellors and care-givers. I was able to see them in action on many occasions. Participants in the workshops that they run appear to have been encouraged by their enthusiasm and motivation and felt comfortable enough to ask questions relating to ARVs, employment, nutrition, disclosure, opportunistic infections etc. The workshop participants

know that they will receive ARV treatment in the near future, and therefore want to know what benefits treatment will give. In other cases, people who are just beginning ARV treatment want to know what the future holds for them. Some questions that were typically asked were: *Has the pain [of HIV] gone away? How long have you been on treatment? Why can you can you only start treatment when your CD4 is less than 200?* These questions can only be answered meaningfully if workshop facilitators are comfortable with disclosing their HIV status, and in support groups they were. Organisations that have benefited from *Mapping our Lives* workshops run by the women reported that the fact that the facilitators were comfortable with their HIV status and prepared to talk openly about it, was really important for the participants in the workshops.

The fact that many of the 'public' disclosures conducted by the women occurred in the context of their outreach work for ASRU is potentially problematic because of the obvious economic benefits. In an area of high unemployment, the fact that the women received a stipend for their activities introduces a kind of 'professional-private' dialectic into the activity of disclosure. This inevitably raises questions as to how 'voluntary' the disclosures actually were. For example, in a discussion quoted in the *LongLife* book, the women discuss how HIV has affected their economic circumstances, after Jonathan Morgan made a statement about a woman he had met stated that she loved HIV because she was getting ZAR1,000 per month in welfare grants. Thembi commented: 'I also love this HIV. Before I was sitting at home, no job, no nothing, now everything is lekker (great). Is that shocking to you Jonathan? Now at least I am hoping.' Sylvia added, 'Me also, I was thin. Thin, thin, thin, thin and not from HIV. It was before I became infected, after my boss went to Australia. I was just thin from no job. Now I'm fat because of my grant and my job which is all about HIV.' Maria added: 'HIV is my friend. Before, only my husband was the breadwinner. Now we combine it [...]. I feel good that I can contribute also.' (Morgan and the BWG: 121-122). From the statements above, it is difficult to disentangle the economic benefits received as a result of the women's involvement in the *LongLife* project or from the government welfare grant. The distinction between the two is important as in the case of the grant, they just get money with no pressure to disclose while in the case of their work there is the pressure to disclosure. Although the women all agreed to become involved in the *LongLife* project before they were offered opportunities to continue the work through ASRU, the fact that ongoing disclosures were linked to work brought with it new pressures as their success in their jobs was to some extent related to their openness with their status.

> I think for me last year it was because every time lets say they [ASRU] send these people to me, they will say but that's what we pay you, that's part of the reason why you are being paid this salary [to run workshops or do presentations]. So in a way I did not have a choice. And I don't really; I am not saying that was bad but sometimes … I really did not want to talk about like anything, like I didn't want to say anything about HIV, but like I felt the pressure. Even though nobody was serious about me because they assumed because I was [connected] to TAC, they assumed that I did not have a problem [to disclose]. But sometimes I had a problem. Sometimes talking about HIV, it's too much for me, and you don't really want to talk about it. But I did not have a choice, they were paying my salary. (Buyiswa)

Some of the women consciously realised the need to be seen as an activist, and wanted to be activists, but they were unsure how ready they were to take on this role in all aspects of their lives. Their professional and activist lives inevitably influence how they think and feel in their private lives. This must be a difficulty faced by all HIV positive people who work in this 'industry'.

> Sometimes the pressure you get, and we needed to promote the book, so I was there to do that. But at the end of the day I felt like that was not necessary for me. I was not the only one to disclose, I was not the only one to go there on public to the different newspapers and disclose and at the end of the day I ended up being angry but I dealt with it because at the end of the day you have to pass any stage in your life. (Buyiswa)

As can be seen in the quote above, there were differences within the group regarding their levels of openness around their HIV status and therefore some felt that they bore an unfair burden to disclosure more often. The group also disagreed on other major issues including disclosure in sexual relationships.

Buyiswa (in the quote above) touched on the problem that in disclosing ones HIV status as a repeated activist activity, it lost its personal meaning and became a performance. Disclosure in this way begins to interfere with the individual's identity, as her positive HIV status becomes the primary aspect of her shared life story. All other aspects of her identity become eclipsed. This is a serious personal cost – and one which had not been anticipated at the start of the project. As can be seen in Buyiswa's comments, the fact that the burden was not shared equally caused further resentment.

6.11 Private disclosure in the interests of 'public' health: helping others

Despite differences in opinion amongst the group, the general consensus was that disclosure is beneficial not only for them as individuals, but also for their society as a whole. Some women used disclosure not necessarily to decrease transmission of HIV, but rather as a way of alleviating others' stress and helping people cope with their positive HIV diagnosis. They used their training as counsellors and peer-educators in conjunction with their personal HIV experience to educate others about voluntary counselling and testing (VCT) and other relevant issues.

> I want to help another people because outside in our communities there are so many people dying because of AIDS, because of HIV. Because they are hiding something. Then if you [are] hiding something then it is going to stress you everyday because you feel alone. Maybe its few who have got this virus ….outside there are so many people have got this virus. Maybe I can help you to go to support group because on Thursdays and Fridays I go to support group. (Dunyiswa)

> … there was a young lady who was HIV positive, but she didn't want to come out with her status. Maybe this week she will come to this clinic in Site B, she will change names, next month she will go to Site C, that month she will go to Harare, changing names. But when Nokwanda sit down with her and talk to her then she felt good, then she come out with her status. (Nokwanda, translated by Nonceba)

In the cases above, disclosure takes on an inter-personal meaning – far beyond that of the 'public' disclosures associated with the *LongLife* project. The more open of the women argue that being openly HIV-positive is important as people who need help in the community are able to approach them. Ntombi is an example of this perspective, and is generally more open with her status than the rest of the group. She claimed not to care about who knew her HIV status and argued that by standing as a positive role model for HAART and by encouraging openness about HIV, she could help combat the epidemic.

> In my community I think they will be more supportive because they always see me as somebody who can help them within the community if they see somebody sick or if

> they know somebody who looks just like with HIV, they will want me to come talk to her. I think in a way I have helped because when I came there they already knew about my status so I became somebody that they can look to and they can relate to. Like if somebody is sick, they can refer that person to me, irrespective of the age. (Ntombi)

Ntombi's attitude reflects the aspirations of the GIPA assumptions about the transformative powers of public disclosure. However, according to Buyiswa, Ntombi's attitude to disclosure was unique in the group. Buyiswa accused the majority of the group of not disclosing in their own communities whilst being happy to disclose everywhere else. She made the obvious point that they would have a far greater effect if they also disclosed their HIV status within their own communities, rather than in safer alternative public spaces. Buyiswa looked at disclosure from a public health and activist perspective, where disclosing to one's household, friends or the community, is not only about one's physical and psychological well-being, but rather intended to get loved ones to take precautions in the future so that they do not get infected.

6.12 Discussion

This chapter has highlighted many of the complex issues involved in the 'public' disclosure of one's HIV positive diagnosis. Disclosure is important for PLWH as it is a key step on the path to accessing appropriate treatment and support. However, when somebody reaches the stage when they need to decide whether to disclose or not, and to whom, they are faced with the fear of negative reactions posed by the stigmatisation of PLWH. The complexity is exacerbated when the individual is disclosing not only for personal gain, but in the interest of the broader public.

Disclosure, especially in the public domain is mediated by the possible risks and benefits involved. The interviews from the women and data from other studies show that perceived negative reactions or perceived stigma is potentially the most significant barrier to disclosure (Chandra *et al* 2003; Greene and Serovich 1996, Bharat and Aggleton 1999). Such dangers are shaped by the specific the socio-economic and cultural context in South Africa but are also similar to many contexts in sub-Saharan Africa. In particular, the social status of women and feminisation of the AIDS epidemic are important contextual factors determining the range of disclosure possibilities available to the women. There is a very real social risk associated with being HIV-positive, as HIV is unlike many other diseases in the way that PLWH may be the

target of discrimination (Joffe 1999; Herek 2002). As a consequence, the women in this study were constantly negotiating which 'public' they are disclosing to in order to minimise the associated risks.

The dynamics of this situation are valuable as they provide us with an insight into the kind of disjuncture between the different types of disclosure based on perceived definitions of community and family, and advocacy, spatial, racial and physical boundaries. The narratives provide us with a basis from which we can begin to understand how a group of African women living in an impoverished setting navigate between their everyday identity and their HIV-positive diagnoses.

The personal stories from the women correlate with the forms of stigma prevalent in Cape Town as described by Maughan-Brown (2008). Their personal stories often contain references to the connection between being HIV-positive and being called promiscuous or "loose women" by people in their neighbourhoods - clearly a form of symbolic stigma (stigma based on moral judgements). Interestingly, while Maughan-Brown (2008) found the lowest levels of stigma based on resource constraints, the women often reported jealousy (and related associations with witchcraft) as a determinate of stigmatising attitudes. Other studies have also found links between competition of resources and stigma, such as PLWH's free access to formula milk to prevent mother-to-child transmission through breastfeeding (Coutsoudis et al 2002).

Because of the activist and advocacy agenda of *LongLife*, public disclosure was an integral and inevitable aspect of the project. While this eventually caused resentment – especially where the burden was unequally shared – the women were able to control to some extent which 'publics' they were disclosing too, and they were able to do so in a way which minimised their exposure in their own communities. The women defined 'public' subjectively and dynamically in order to minimise the risks on their personal lives. The in-depth interviews illustrated the way that specific 'publics' were perceived according to spatial and racial considerations. The women in general felt more comfortable disclosing outside their communities (even in parts of Khayelitsha they did not live in), and in further flung residential and business areas where the possibility of identification was minimal. On the other hand, telling their stories in public in place like Khayelitsha or another township needed careful consideration. For example, at the funeral of Ntombi's son in Khayelitsha, Professor Nicoli Nattrass was invited to speak as Ntombi's employer at ASRU but she was explicitly told not to mention HIV (even though she was one of the few women who approved of printing both their name and surname in the

LongLife book). 'Public' is therefore not as all-inclusive as the introductory paragraph in the *LongLife* book.

A common feature of all the narratives was the perception that non-black African racial groups are more understanding and they therefore feel comfortable disclosing in other communities where the majority of the people are white or coloured (as in the case of their presentations at the South African National Gallery in the Cape Town city centre). However, according to the data from both the HSRC/Nelson Mandela Study and the Cape Area Panel Study, AIDS-stigma was actually higher amongst coloured and white people than amongst Africans (Shisana and Simbayi 2003, Maughan-Brown 2008). This disjuncture between the perceptions of the research participants and the survey data described above may indicate that the issue is more about minimising personal risk in an uncertain social environment.

If we look at the risks and benefits of public disclosure, as in the different types of public spaces discussed above (including mass media), the benefits of this kind of disclosure relate to the professional aspect of the women's lives, while the risks affect the personal lives of the women. However, locating where the particular risks and benefits are is complex, as many benefits in the professional realm are also personal benefits. Public discussions about the book and the bodymaps increased public awareness of the *LongLife* book, thereby increasing demand for the book and bodymap workshops – both of which benefited the women financially. The book also became the exhibition catalogue (for the body map exhibitions), so despite the limited amount of information on the bodymaps, the book was always available and this of course included detailed narratives and conversations about the private lives and histories of the group of women. In some ways, public disclosure, or the telling of their private stories, can be equated with advertising and marketing of the 'Bambanani Women' as HIV peer-education experts. From an income perspective, the increased demand would mean increased financial returns for their peer-education and advocacy services, and royalties from the sale of the books and bodymap prints. Sylvia, Buyiswa and Thembi are examples of this, as demand for their expertise has meant that they have travelled throughout South Africa, to Europe and the USA.

In some ways, the more risk some women took by not being concerned with disclosure audiences, the more in demand they were by AIDS advocacy projects and NGOs (hence the higher the return so to speak). Yet the more they disclosed, the higher the chances were of being identified as HIV positive in their communities. Each of the women interviewed crafted

their own personal strategies of disclosure which minimised the risks whilst maximising the potential benefits as they saw them. But this, in turn, undermined the 'group' aspect of their professional lives, with tasks, activities, and eventually jobs being determined on an individual rather than group basis.

The 'public' contributions of the women were not restricted to disclosing and discussing their HIV status to large numbers of people. Through the training, capacity building and empowerment provided by ASRU, MSF and TAC, many became 'experts' on HIV/AIDS and were able to give personal advice and counselling on an informal basis to others in their communities. . This may well have been more meaningful than the 'performative' disclosure in front of TV cameras, art exhibitions etc. which occurred at the height of the *LongLife* project. It may well be that 'low key' disclosure has had more of an impact on society than a book like *LongLife* and related art exhibitions. *LongLife* is written in English and is relatively expensive, while in the more community-located and private spaces, the women could pay special attention to individuals and small groups of people. They could help them cope with the stress of living with HIV through more personal attention. Even so, it is difficult to compare the benefits and costs of the public advocacy arm of their work with their more community based activities. To the extent that *LongLife* was part of a social movement to put pressure on the Mbeki government to provide HAART to others, it may well have helped save many thousands of lives in the process.

From an interventionist perspective, ASRU and MSF may be criticised for putting these women at risk through a public project such as *LongLife* by offering them the attraction of a decent income linked to work which entails disclosure. However, Meursing (1997) and Paxton (2002) argue that a reasonable wage is essential to recognise the important contributions PLWH can make to prevention, education and care interventions. This income may increase self-esteem for those with fragile income security and may contribute to household income as well as keeping these educators alive and healthy for longer so that they can remain positive and contributing members of their respective communities.

In the final analysis, it is probably fair to say that the women made a meaningful contribution to the struggle of PLWH to get access to life-saving ARV treatment through *LongLife*. They used their life narratives to show that treatment had changed their lives and that arguments regarding unaffordability and toxicity of ARV medicines were clouding the moral issue that all people including the poor have the right to treatment. The project also fed into the broader

advocacy agenda which already called on the government to rollout HAART. However, the analysis above has also shown that the women's activist, professional and private lives are intricately intertwined, specifically as disclosure was fundamental to their success in the role. And while the risk was limited to how well they were able to implement their roles in their jobs (as they had some choice whether to disclose or not), when they did decide to disclose the risk was very apparent in their personal and private lives due to the stigmatised nature of HIV-disease. The next chapter moves from understanding the dynamics of public disclosure and for largely activist reasons to analysing disclosure in the household and neighbourhood contexts often to significant others who are relied upon for critical support.

Chapter 7: Why do PLWH disclose? The dynamics of disclosure to significant others

This chapter analyses the narratives of the same group of HIV-positive women discussed in Chapter 6, moving the lens from the wider sphere of public disclosure to the micro environment of disclosure to significant others – mostly within the household context. This chapter combines primary qualitative data (in depth interviews) with relevant local and international research to explore the biophysical, individual and social contexts that shape, and in turn are shaped by, the disclosure of HIV status to others.

The previous chapter explored the ambiguities of public disclosure, highlighting the complex dialectical relationship between the public and private lives of this group of women, some of whom were activists. The women defined 'public' subjectively and dynamically in order to minimise the risks for their personal lives. The participants' accounts of disclosure illustrated the way in which specific 'publics' were perceived according to spatial and racial considerations. Chapter 6 argued that the women felt more comfortable disclosing outside their individual communities (that is, outside Khayelitsha), and in other areas (such as universities and art galleries) where the possibility of identification was minimal. The analysis highlighted the ways in which subjective perceptions of social distance mediated the public disclosure process, through a process of identifying a spatial map of 'risky' environments, and those where safety of their HIV-status would be most likely. By using such strategies, the project participants were able to contribute to the advocacy agenda of the *LongLife* intervention, while minimising the personal risks posed by public disclosure.

This chapter explores, contrasts and discusses the participants' experiences of living with HIV in the household context – specifically the ways in which the dynamic HIV-disease experience interacts with the disclosure process in both individual and social spheres. Following on from the discussion of the wider social context of HIV in Chapters 4, 5 and 6, this chapter first contextualizes the disclosure process though probing the participants' experiences of community views on HIV/AIDS and illness, and then explores motivations to disclose to household members and the consequent outcomes.

Studies on disclosure of HIV status in both developed countries (Greene et al, 2003, Petrak et al, 2001; Petronio, 2002, Serovich, 2000, 2001; Schmidt and Goggin, 2002) and developing

countries (Chandra et al, 2003; Soskolne et al, 2003; Kahn, 2004) show that the decision to disclose is generally a difficult process. PLWH are confronted with numerous factors that compel, encourage or constrain disclosure. Cline and Boyd (1993) point out that, 'the dilemma faced by persons with HIV/AIDS is this: either risk becoming stigmatised by disclosing their condition, in order to take a chance on gaining the potential health benefits of social support, or avoid being stigmatised by engaging in information control and nondisclosure, thereby losing the potential health benefits of social support' (Ibid: 132).

Even as early as 1999, in a study conducted with HIV-positive women in out-patient clinics around Cape Town, of the 51% of respondents who had disclosed their status to at least one person, 89% reported either no change or an improvement in relational quality (Mathews et al, 1999). A recent literature review of disclosure in developing countries reported that most outcomes to disclosure were positive (Medley et al, 2004). According to Coetzee and Nattrass (2004) analysis of data collected by MSF from their HAART patients, 82% had disclosed to one or more family member (2004).

Disclosure can be beneficial for PLWH as well as their households, sexual partners and public-health in general. As the psychology literature shows, disclosure usually has a positive relationship with psychological well-being, as disclosure is thought to lower stress levels, which leads to better psychological health and quality of life (Pennebaker et al, 1990). Disclosure may also help PLWH access the necessary social support, treatment and care they require, and facilitate improved adherence to HAART regimens (Skhosana et al, 2006) and better informed reproductive decision-making (Simbayi et al 2007). However, as pointed out in Chapter 5, there are also costs (potential stigma) so the process of disclosure ultimately involves a highly contextualised process of risk-benefit assessment (also described in Chapter 6).

7.1 Experiences of disclosure

The chapter now turns to a description and discussion of the disclosure narratives of the eleven HIV-positive women who participated in the study.

'If you get sick, people will assume your positive status': Community perceptions of HIV/AIDS

> You know when you are very sick, people are suspicious. Because now [as] an HIV-positive person you [are] sometimes becoming very sick, so people are suspecting that you may be or you must be positive. (Lizeka)

> If you get sick, people will assume your positive status even before you have tested for HIV. People might judge you as being HIV-positive because you look sick. (Buyiswa)

Lizeka and Buyiswa are referring to their communities' understanding of the perceived link between illness and HIV. Another participant, Nonceba, highlights specific opportunistic infections common to stage three and stage four that are often seen as markers of a positive HIV status:

> As long as you have lost weight and you dropped your weight down, then they will say 'Phew, she's HIV-positive'. (Nonceba)

Nonceba (whose health was restored by HAART) adds that stigmatising attitudes were expressed by her community because she 'looked' like she was infected with HIV even though she had not at the time yet been diagnosed HIV-positive.

> … Like they saw me walking on the streets, they will say, 'There is that bitch that has got AIDS.' So, all those things, they are not good to hear. Like before I know my status while I was very, very sick, so they were always saying that that lady has AIDS. But now that I am well, I am fine; they don't have those words again. (Nonceba)

Although her health improved dramatically after starting HAART (her CD4 count was zero at the time), the scarring left by skin rashes were a constant possible identifier of her positive HIV status.

> Like I had those sores on my face, so even while … I was taking the treatment in Site C [a part of Khayelitsha], while I was passing [over] the road from home to the Cite C clinic, I used to pass next to the [taxi] rank, so the taxi driver used to just come and look at me, 'Oh, you can just see from her face that she has AIDS.' (Nonceba)

On the other hand, a healthy body may be wrongly assumed to be an 'HIV-negative body'. The KSPS 2004/5 survey of PLWA on HAART (see Chapter 4 for more details) showed that 85% of respondents agreed or strongly agreed with the statement: "When I look very healthy, people do not believe I am HIV-positive." Only 4% disagreed with this statement and 11% were unsure. The debate within the group on the challenges faced by PLWA paid a lot of attention to the fact that community perceptions of HIV are very closely linked to physical appearance and to bodily illness as a signifier of infection.

> What Nokwanda is saying is that her community knows that she is HIV, because she disclosed to them….but because now she is well they don't believe anymore. So she doesn't understand why [the community thinks that] someone with HIV must have horns or… look different. (Nokwanda translated by Sylvia)

Sylvia's experience of disclosure to her immediate family in the Eastern Cape is a poignant description of the perception that HIV is recognisable in the popular imagination. In 2004 Sylvia had known her HIV-positive status for 5 years, but her immune system had coped extremely well and she was not experienced severe opportunistic infections. She disclosed to her brother nine months after she was diagnosed because she was confident that he would give her support (as he was also HIV-positive and had previously disclosed to her). She was, however, reluctant to disclose to the rest of her family because she had heard one of her sisters speak negatively about PLWH. It took her two years to decide to disclose to the rest of her family. This took place when she went back to the Eastern Cape for the holidays.

One afternoon, after slaughtering a cow, all the women were sitting inside the house, when her sister told her about a woman who had disclosed her HIV-status to her family. Sylvia's sister then asked her about her job that she knew involved HIV/AIDS.[51] Sylvia then called all her siblings and her mother together and told them that she would tell them something and then tell them more about her work. She described her story – from when she was diagnosed HIV-positive while pregnant, and took AZT so she would not infect her child, to when she began to get involved in AIDS-related advocacy work (including the *LongLife* project). Her family did not believe her and thought she was lying.

[51] At the time of the interviews, Sylvia was facilitating peer-education and psychosocial support workshops in support groups for PLWH in clinics.

> And then my sister looked at me and also my mother looked at me. They say you so fat but you say you HIV-positive. I said, 'Don't point fingers … You can be thin because of stress … HIV-positive people [are] not thin.' If I tell the people here in the Eastern Cape I am HIV-positive, they won't believe me. (Sylvia)

Her sister and her mother did not believe that she was HIV-positive as she was looking very healthy. They asked her if they could phone somebody to confirm that she was indeed HIV-positive. Sylvia phoned her employer who confirmed her HIV status.[52] They still did not believe. Sylvia knew of another woman who worked for Wolanani, an income-generation project for PLWH in Cape Town, who was in the Eastern Cape at the time. She asked her to come to her family's home to tell them about her HIV status. It was only after this woman came to visit Sylvia's family that they finally believed that she was indeed HIV-positive.

Lizeka, also tells of disbelief when she disclosed her status to her mother.

> … she didn't understand, [s]he didn't believe … because she said, 'No you are lying. People who have got AIDS [are] sick ... If you are lying on the bed and are sick, they [the community] understand. (Lizeka)

From a different perspective, the data suggests that some people may be confused about their own HIV status due to the community's reaction to them after they disclose. Sylvia said that if she did not have adequate HIV knowledge, she would have begun to doubt her own HIV-positive status.

> If I am not in my house, [or] they don't see me for two days, they will come and like people who like support me in my community always come to see if I am sick or something. Some of them say, 'No, [we never] see you really being sick. And your children are healthy. Why do you think you have HIV? Because what if the test was wrong.' Because of that, if I did not have enough information about HIV, I will doubt my status because people will really make you doubt if you are really HIV-positive, because of the things that they say when you are not sick. (Sylvia)

Zoliswa summed up the confusion surrounding the manifestations of HIV/AIDS when she spoke of the importance of public disclosure and knowledge of public sector HAART rollout.

[52] Vicotira's employer at the time was Jonathan Morgan, the director of the Memory Box Project at ASRU.

> It's important to do that, to disclose to the community. Because maybe … my community … saw I was sick, then they saw me while I was putting [on] weight. They are confused. 'What is going on [with] Zoliswa, because we don't know now before?' Maybe before they say … that 'I think she is HIV'. But then they saw me [putting on] weight. Say, 'Ooh I don't know what is going on?' So the community they must know, you can get sick, but there is something that can help you … and your life is coming back again. (Zoliswa)

However, community perceptions of HIV/AIDS are not exclusively innocent misunderstandings of the aetiology of HIV/AIDS, but include more malicious attitudes towards PLWH, especially women. Within such a context, people fear being identified as being HIV-positive and hence fear disclosure.

7.2 Culture, gender and the manifestations of stigma

According to the majority of the participants' narratives, the overriding anxiety of being identified as HIV-positive is largely based on fears of 'gossip' (Almeleh 2004). Gossip seems to be the most common and hurtful form of discriminatory attitudes experienced by the participants within the community context. Participants retell experiences where they hear that they are labelled as promiscuous, prostitutes, witches, cursed or 'loose' women, especially when they are identified as or assumed to be HIV-positive when they are visibly ill.

> On my side, to my community, I won't disclose to them. Because the other day when I was at home sitting with my child and my child was very young and then they ask me. The other lady was lustig [curious in an unseemly way]. My neighbour asked me why I didn't breastfeed my child. I just told her I have got a problem to my breast. So she just spread it to the other people, why I am not breastfeeding my child. When I found out she was talking bad about me, I told myself I am not going to tell the community about myself. And the other thing, they are always asking me why I have got the formula milk, and 'where do I get the formula milk because I am not working and also my boyfriend is not looking after me?' So I told myself, where I am staying now, I am not going to disclose to them because they are very curious. They want to know what is going on in your house so that they can say bad things outside about you. (Sylvia)

Sylvia explains further:

> Because if you walk, come out of your gate and you walk out in the street, you see the people making some funny jokes. So that thing can hurt you because you disclosed to them now they got stigma on you now. (Sylvia)

As noted in Chapter 6, Thembi expressed similar sentiments, worrying in particular about 'gossip and jealousy' and the 'big mamas' who 'practice witchcraft and all this things'

In a study done in KTC, a low-income township in close proximity to Khayelitsha, Mills found similar instances of 'gossip' and blame. People who were identified as being HIV-positive were said to have 'too much sex', 'too many boyfriends or girlfriends' or told they were promiscuous and unfaithful (Mills 2004:8). The perception of PLWH having too many partners is backed up by research on the same KSPS data set by Maughan-Brown et al (2009) where the researchers compared levels of concurrency between patients on HAART and a matched sample from a related survey amongst the general adult population in Khayelitsha. They found that the prevalence of reported concurrency was relatively high among HAART patients and in the general population (24% and 18% respectively) and that perceived concurrency among the study populations' sexual partners was higher among HAART patients (35% versus 20%). Importantly, the analysis from the study above also showed that more men reported having other partners than women and more women reported that their male partner definitely had other sexual partners (41% compared with 15%).

Nadine France (2004) describes gendered moralistic judgments in her research on the causes and experiences of stigma in Africa.

> In almost all interviews, women were cited as suffering more from stigma – 'they are blamed for the spread of HIV by their partners and families which is related to notions of promiscuity. Women suffer because they come out whereas men hide their status and blame women'. 'If a woman is HIV+, she is blamed for infecting the man. If the man is sick it is seen as an unfortunate stroke of luck – he is given sympathy and not blamed'.[53] (France 2004:3)

[53] France (2001) quotes focus group discussions with religious leaders in Botswana/Namibia in March (2001), and in Tanga, rural Tanzania, April (2001).

These experiences, as well as those documented in many other studies demonstrate the link between experiences of stigma and the gendered nature of HIV in sub-Saharan Africa (LeClerc-Madlala, 2001). Women are seen as one of the vectors of HIV transmission for a number of reasons. Firstly, more women are infected than men, and rates of HIV-infection amongst young women are significantly higher than young men (HSRC 2009. Secondly, women are more knowledgeable than men with regards to their HIV-status as they are tested more frequently than men due to a higher frequency of interaction with the medical sector, specifically during antenatal care. The higher numbers of women accessing HAART than men is an additional indication of their generally higher levels of health-seeking behaviour and interactions with the medical sector (Nattrass 2008c). Due to these factors, women are most often in the position of being the first to disclose their HIV status in a relationship – and therefore likely to be accused of bringing HIV into relationships. Men visit VCT sites less often than women and, at least up into the mid 2000s, typically did not know their HIV status until they were in the final stages of HIV infection (Skhosana et al, 2006). As a TAC activist described to Orford[54] (2006) when referring to the high incidence of violence against HIV-positive women:

> "We need men who have HIV to speak out. By speaking out they would show that it [HIV] is not just a woman's problem. Women get tested when they are pregnant – that is when many are diagnosed – so HIV is associated with women. Men think that it is women who carry the disease, because women are always first to know. Men don't test because they see it as a woman's problem and they only seek treatment when they are very sick." (Nomfundo Dubula, a TAC activist, in Orford 2006: 80)

There is also a strong political-economic dimension to the HIV/AIDS environment in which disclosure must take place. The South African government under Mbeki was also to blame for contributing to a context in which PLWH were more likely to keep their HIV status a secret due to its misguided education and prevention messages and protracted (but ultimately unsuccessful) attempt to prevent the public rollout of HAART (Nattrass 2007, Mills 2008). As Nathan Geffen (the previous Policy, Research and Communications Co-ordinator at TAC) stated in 2000:

> Everywhere we go, we hear: "HIV/AIDS is a death sentence" or worse, "There is no cure—education and prevention is the only protection". From these primitive HIV/AIDS messages, millions of people learn fear, hopelessness, loneliness and anger. These messages promote fear and anger that result in prejudice, discrimination and violence

[54] http://www.feministafrica.org/index.php/deadly-cost

> against people with HIV/AIDS. Government messages fail to tell the millions of PLWH that it is possible to live fully and productively for many years. They don't explain to people with HIV how to live healthily or that opportunistic infections like TB can be prevented and cured. Above all, they ignore the fact that millions of lives could be saved if people with HIV/AIDS had access to treatment with anti-retroviral drugs. (Geffen 2000)[55]

However, beyond these socio-structural constraints, even if men did disclose first, women may still be blamed for bringing the misfortune of illness into the relationship. The story of Fana Khaba adds substance to the idea that women are blamed for misfortune, including HIV/AIDS. In the book Khabzela, Lyn McGregor tells the story of Fana Khaba (DJ Khabzela), a popular Johannesburg Radio disk jockey who rejected HAART and died from AIDS after an unsuccessful search for alternative therapies. Khaba's fiancé, Sibongile, described how she was blamed for the death of Khaba (McGregor, 2005:177-8). His affliction with AIDS was blamed on witchcraft and related occult forces (for example, loss of protection from ancestors) – factors which are often are blamed on women.

Ashforth (2005) draws on ethnographic research in Soweto, Johannesburg to provide valuable insights into the links between HIV/AIDS, witchcraft, gossip and jealousy. Ashforth argues that common symptoms of AIDS, such as persistent coughing, diarrhoea, abdominal pains and wasting 'have long been associated in this part of the world with the malicious assaults of witches' (2005: 9). Furthermore, Ashforth argues that gossip is the medium through which moralistic judgements are made about community members. Gossip therefore feeds envy and jealousy which are the motive forces of witchcraft (*Ibid.*: 67). In Stadler's (2003) research on HIV/AIDS prevention in the South African lowveld, he reports the links between the popular understanding of HIV/AIDS, gossip, witchcraft and AIDS-stigma. Stadler argues that a combination of the South African government's questioning of the science of HIV/AIDS (linking in to Nathan Geffen's statement above) in addition to moral panic fostered by gossip have had far-reaching and damaging consequences for prevention efforts in South Africa. Gossip is an ideal method to fuel both stigma and misunderstandings of HIV/AIDS. Gossip is more likely to affect women, include indigenous understandings of HIV/AIDS (i.e. AIDS is caused by witchcraft), and include moral judgements of the people being gossiped about – all important characteristics of the group putting others at risk.

[55] http://www.tac.org.za/Documents/Statements/pr000823.txt

The narratives of the women resonate with Ashforth's and Stadler's analyses. Thembi, for example, blames the 'stigmatising' gossip on the 'witches' in her community, while other women attribute gossip to potential jealousy, for example, when they were seen collecting social grants, food parcels and formula milk (see also Coutsoudis et al 2002). According to Gluckman (1963), gossip is an integral part of all aspects of community life, and has the ability to unite the community or set it against a particular group. In the case of Thembi's anecdote, the 'big mamas' who are gossiping are uniting (and protecting) themselves against HIV-positive people who pose a risk to their communities, dovetailing with Helene Joffe's notion of the 'risk group'.

Avoiding and challenging stigmatising attitudes (characterised by blame and gossip) in the community, while simultaneously accessing treatment, care and support is the tricky path PLWH have to negotiate. In this sense, the life experiences of PLWH are bounded by their social context and their individual actions are a response to their environments. However, as discussed below, their actions both reflect and challenge existing community stereotypes about HIV.

7.3 How do individual experiences interplay with the social context?

The participants of this study encountered VCT when they were either pregnant or sick (see Table 7.1). In Tanzania, Maman et al (2001) also found that women's decisions to access VCT were motivated by their reproductive health problems (pregnancy), own sickness, or the sickness or death of a child or partner. The 2005 HSRC survey also found a significant percentage of respondents used VCT services because they were pregnant or they were sick (Shisana et al, 2005:83).

Because people are getting tested when they are sick or pregnant and only disclosing in the later stages of HIV-disease, HIV/AIDS would likely be perceived as an illness that begins with a seriously compromised health-status and ends with death, unless HAART is introduced. The first two stages, in which only slight or mild symptoms are experienced (see Table 3.1 in Chapter 3), do not seem to influence the perception that good health is possible when somebody is HIV-positive.

This study supports such a hypothesis. Approximately half of the study participants were diagnosed when they were sick (with visible signs of AIDS-related illness such as weight-loss; skin problems etc.) and disclosed (to at least one family member) soon after due to their

compromised health status and a need for health-related social support. Those that were diagnosed while pregnant and healthy took far longer to disclose and disclosed to fewer people. Because most of the women disclosed while seriously ill, this probably reinforced community-level stereotypes linking HIV infection with visible illness.

If HIV-positive people disclose while healthy, popular perceptions can be challenged. This, however, is difficult to do because of concerns about rejection, gossip etc. Because HIV-positive people can live many years without any signs of illness, the decision to disclose can be delayed (Loewenson and Whiteside 1997). If the person is unwilling to risk possible stigmatisation, he or she will probably not disclose and may not access appropriate social support and medical treatment. As the individual progresses to the more serious symptomatic and visible phases, such non-disclosure indicates that he or she is probably not accessing the necessary levels of care.

The timing of diagnosis is a critical factor in the disclosure process (see Table 7.1 below). People learn of their status at different points on the biophysical HIV trajectory, which inevitably affects the ways in which they are able to deal with a positive diagnosis. For example, if the person is visibly sick with weight-loss, TB or skin rashes, yet has not disclosed, he or she may be assumed HIV-positive as in the cases of Nonceba, Lizeka, Zoliswa and Liziwe. In a study of lay health beliefs regarding HIV/AIDS in East Africa, Nicol et al (1993) found that people thought they were able to recognise an HIV-infected person by observing his or her weight. On the other hand, interviews conducted with the respondents for this study showed that if the person is healthy (stage 1 or stage 2, and asymptomatic) when they are diagnosed and disclose during a phase of good health, people questioned their HIV-positive diagnoses, as in the cases of Sylvia and Buyiswa. It thus appears that if you are healthy and HIV-positive the community may not believe you, and if you are visibly sick and/or identified as HIV-positive, you may be stigmatised.

7.4 What are the motivations for disclosure?

The qualitative data suggest two key motivations for disclosure; to access health-related social support (individually-focussed), and to educate others about the realities of HIV/AIDS (socially-focussed). The data shows the complexity of the disclosure process, where additional motivations interplay with the primary motivations. These include: maintaining control over treatment and care requirements; attempts to improve and maintain psychological well-being; sustaining and nurturing significant relationships; and countering prevailing misconceptions around the

relationship between HIV/AIDS and health. The following excerpts from the in-depth interviews shed light on the process of disclosure and the relevant motivations to these significant others.

Table 7.1: Context and Motivation of Initial Disclosure to Significant Others

Name	Motivation for seeking an HIV test	Health Status at 1st Disclosure	Time between diagnosis and disclosure	Motivation to Disclose	
				Think about the first time you disclosed:	
				Who did you disclose to?	Why did you disclose? (quotes from self-administered questionnaire)
Buyiswa	Pregnant	Healthy	0 years	Friend and mother	'I disclosed a few hours after I was diagnosed. It was just something I wanted to do.'
Dunyiswa	Pregnant	Healthy	Approx. 2 years	Boyfriend	'He used to badmouth PLWH, so I hated that, so I decided to disclose to him.'
Lizeka	Pregnant	Healthy	9 months	Boyfriend	'Because I wanted him to be carefully about the HIV and get tested and use condom always'
Liziwe	Sick	Sick	0 years	Sister	'She was my caregiver'
Sylvia	Pregnant	Healthy	9 months	Brother	'Because I wanted support from one of my family member knows about my health'
Nokwanda	Sick	Sick	0 years	Mother and cousin-sister	'I disclosed because the illness was not getting better, and my mother was going up and down trying to seek for help'
Nonceba	Baby HIV+	Sick	3 years	Mother	'I was going to start ARV treatment and I needed an assistant and I was staying with her.'
Thembi	Sick	Sick	0 years	Brother	'Closest person to me'
Ntombi	Sick	Sick	0 years	Mother	'I knew that I was going to die so I wanted to tell her before I die'
Zameka	Pregnant	Healthy	Approx. 2 years	Mother	'She had a problem with her partner; he had sexual transmitted disease, so advice her to go for a test, she was afraid, so I told her she is going to be fine because I am also HIV-positive.'
Zoliswa	Sick	Sick	0 years	Brother and Sister	'I was sick. I had TB.'

7.5 Who do PLWH disclose to?

The study participants were highly selective over who they would disclose to (see Table 7.1). Mothers were the most frequent disclosure recipient when the participants disclosed for the first time. Other disclosure recipients include (in order of frequency); brothers, sisters, boyfriends, cousin-sisters and friends. This is consistent with other studies, where immediate family members were usually the first people to receive HIV diagnosis information (Armistead et al, 1999;

O'Brien et al, 2003; Chandra et al, 2003; Greene and Serovich, 1996; Schmidt and Goggin, 2002). These disclosure patterns are also consistent with the quantitative analysis in Chapter 9. Kahn (2004) found similar motivations for disclosure in her qualitative study of disclosure in another low-income area near Cape Town where her research participants strongly advocated disclosure within the household context as a means of mobilising support. In this study, women (mothers and sisters) were the most frequent disclosure recipients followed by siblings, other family members, partners and friends. After mothers, disclosure recipients included significant others of both genders. Out of the six cases where disclosure took place during ill-health, five of the disclosure recipients included either mothers or sisters. The data suggests that women are the providers of health-related social support, while other family members provide much needed additional psycho-social support (especially when disclosure occurred while healthy). The gendered nature of disclosure recipients may also be attributed to the fact that all the research participants were women and would likely choose other women for support.

7.6 Setting the scene

The timing of the disclosure was very important for many of the women. Some of the women said that they waited until they had 'accepted' their status and were ready to tell others, while others needed either to test what reaction they would get when they disclosed by bringing up HIV/AIDS in conversation or displaying HIV/AIDS-related materials. Timing was also affected by the time taken to select the correct person and to analyse the potential consequences of the disclosure.

> But for me I always say … you cannot say I am going to disclose and such and such a thing, you have to be ready. As a person and you have to be, you have to know what you will be dealing with after you have disclosed. So I cannot say when is the right time to disclose. I always tell everybody that it has to be within you. But it is important that one member of your family, more especially, not the public, knows your status because at the end of the day you will definitely need the support from your family and from friends, because mostly what is important is for you to get support from people that really care about you. (Buyiswa)

Buyiswa is adamant about disclosing for the correct reasons and to the correct people, and she realises that who the 'correct' person is will vary from individual to individual. Thembi describes the questions that she asked herself before she disclosed.

> First of all you must know what kind of person you going to disclose to. Is this person important to you? Is it important for you to disclose to this person? Why are you disclosing to this person, the reasons why you are disclosing, you know. Then after that, if the person reacts in a different way, how are you going to handle the person, you know? You going to talk to this person and maybe educate and let the person know, what are your weaknesses, what are your fears about disclosure, so that the person understands. And the situation where you disclose it can be different. Also you must also first think about the person, how the person is going to feel. You must not only think about how you are going to feel. (Thembi)

The timing of the disclosure is an important part of the process. In some cases this is due to the person wanting to test whether the person they will disclose to is ready to receive their disclosure information. For Thembi (above) it was about testing how the person would feel (other-focussed), while Sylvia waited until her family members displayed more acceptance towards PLWH (self-focussed):

> I thought they [needed to] change their attitude. Because when I visited them … one of my sisters tried to talk bad about people living with this virus. So I told myself I am not going to disclose my, I will wait till I get the time to disclose to them. (Sylvia)

Lizeka (below) also had to come to terms with her HIV diagnosis in order to be psychologically prepared for the potential consequences. When Lizeka finally decided to disclose, she tested her friends and family's reaction by leaving the *LongLife* book (which included her story) with them, in order to gauge their reaction.

> I was hiding too. What are you going to start with you know? But I took the book, the *LongLife* book, and I put it in a room and then they I go to the bathroom and I go to wash and then they came there and then they see that, they saw that book and they read it and they ask me, 'Lizeka, what is this about?' I told them 'You read in that book what is written there, so it's the truth.' So they told me, the other one, she told me that 'Me too I

> am HIV-positive, so we are friends and we are the family.' So they supported me, no problem. (Lizeka)

7.7 Disclosing due to health-related concerns

Although setting the scene for disclosure was very important, many of the women waited some time until the need for health-related support, to a large extent, 'forced' them to disclose. Lizeka's story was typical. She tested positive in July 2000, and disclosed her status to her mother in October that year because she was experiencing serious opportunistic infections and was not getting better. Lizeka felt a responsibility to disclose to her mother because her mother was trying to help and care for her and she needed appropriate treatment. Although she was sick and in a caring environment, Lizeka, like others, still found it difficult to disclose.

In 2001, Lizeka was diagnosed HIV-positive. She disclosed to her family soon thereafter because she was sick with TB, but kept her status hidden from her friends as she was not ready for possible negative reactions. Thembi, who also disclosed to her family soon after her diagnosis, connects her visible signs of illness (skin rash) to having no choice but to disclose.

> It's because of my skin problem. That is the reason that is making me disclose. Because they are going to ask me: 'What happened to your skin, why is your skin like this and all that.' I have to lie, it's not good lying. I am going to tell the truth. So that is one of the reasons that makes me disclose … Otherwise maybe if I didn't have a skin problem, I wouldn't be disclosing. (Thembi)

Nokwanda reached a stage where her health was compromised to the degree that she was unable to do normal daily activities.

> She said she was very sick, she couldn't bath herself, she couldn't walk, she needed somebody to feed her, she couldn't do anything, so that's why she decided to disclose so that the people they can help her and they can give their support. (Nokwanda, translated by Sylvia)

In Nonceba's case, although she had negative experiences in her community she wanted to disclose to her significant others. She too was experiencing serious opportunistic infections and

required appropriate support. HIV is different to other diseases and she realised that it was necessary that the person looking after her needed to know exactly 'where to go and what to do'. She feared that the incorrect treatment would lead to a further deterioration of her already compromised health status.

Nonceba and Thembi share similar experiences with many of the other participants. Their decision to disclose was at first bounded by fear of stigma. The fear was overcome by a need to engage with their significant others in order to deal with the physical manifestations of HIV disease. All of these women carefully selected their disclosure recipients, and in all cases, support and care continued.

7.8 Maintaining control over treatment options

The relevance of disclosing out of personal health concerns is not limited to seeking health-related support, but to the particular treatment and care required. Both Ntombi and Lizeka feared being sent to a traditional healer if they became ill. Ntombi connects her fears of ineffective and potentially harmful traditional medicine (which often entailed the use of purgatives) to disclosure.

> But if you are sad, you won't tell the people what's wrong with you. Us black people, we believe in the sangomas. Sometimes the people take you to the sangomas[56] and they make it [HIV] worse, because the medicine, the herbs or the sangoma, they are very strong for us. (Ntombi)

Zoliswa and Dunyiswa agree with Ntombi's lack of trust in traditional medicine and place importance on getting the correct treatment for HIV. It is important to note that all of these women have been on treatment literacy courses facilitated by the Treatment Action Campaign (see Ashforth and Nattrass 2006) and had received further education and through ASRU (as described in Chapter 6). Educational messages include explanations of how traditional medicines can undermine HAART both through its purgative effects and via potentially harmful pharmacological reactions to HIV medications.

[56] Sangomas are the traditional healers in the Zulu, Swazi, Xhosa and Ndebele traditions in southern Africa. They perform a holistic and symbolic form of healing, based on the belief that ancestors guide, protect and punish the living. Sangomas are consulted to heal, and through them ancestors from the spirit world can give instruction and advice to heal illness, social disharmony and spiritual difficulties (Green 1999; Kale 1995)

> … So I don't want my family to take me to the traditional healers ... Maybe the traditional healer gives you strong medicine and then you become weaker and weaker and weaker, and end up dying. (Zoliswa)

The decision to disclose is carefully managed and timed by the individual in order maintain control over their treatment and care options, and hence receive selected forms of support. In Zoliswa and Ntombi's cases, they were motivated to disclose as they did not want to be taken to traditional healers, but rather to their clinic doctors.

The interplay between the western biomedical and the traditional healing paradigms is interesting and complex. Data from the KSPS 2004 survey shows that 16% of respondents claimed to have been to either one or more sangomas prior to starting HAART. Of those 40 respondents, only two reported visiting traditional healers after having started HAART. HAART patients undergo intensive HIV/AIDS education and HAART treatment literacy prior to beginning treatment. All the participants in this study have high levels of HIV/AIDS and ARV knowledge from organisations such as MSF and TAC. This education is strongly based within the biomedical paradigm (Ashforth and Nattrass 2006). Anecdotal evidence suggests that educators and health professionals discourage the use of traditional medicine. This point is evident from the *LongLife* book where Dunyiswa states:

> I think if you are going to take traditional medicines you need to talk to your doctor about them, but because MSF emphasise ARVs, that cause us to keep quiet about what we are doing with traditional medicines. (Dunyiswa in Morgan and the Bambanani Women's Group, 2003:72).

Biomedicine has proven success for every member of the group, because they have either seen their own health improve dramatically due to HAART or have taken a short course of ARVs as part of a PMTCT program.

7.9 Accepting advice from health professionals

Disclosure in times of ill health is not only a necessary choice of the person living with HIV, but also a recommended decision from the health-care perspective (Department of Health 2004). Nonceba and Lizeka describe their experiences with health-care workers:

> The nurse was told me: 'Disclose to your mother or one member in your family'. I said, 'No.' She said to me, 'You must choose the right person then you must disclose. Then if you are sick, they can take you to the hospital.' (Nonceba)

> My cousin-sister for example, she's the nursing sister here in Jooste Hospital. She just took me to MSF. I didn't know anything about MSF. So the minute I told her that I am HIV-positive, she went to find help for me ... I can say that our relationship was [better] when she heard that I am HIV-positive, than before. (Lizeka)

It is common for health-care workers to encourage disclosure. This was evident in the 2004 National Treatment Guidelines, in which, under psychosocial criteria for starting HAART, it states that it is 'strongly recommended that clients have disclosed their HIV status to at least one friend or family member' (Department of Health, 2004). Health-care workers realise that appropriate social support (specifically related to the HIV condition) and thus good adherence is unlikely in the absence of disclosure to those that can give support. Those health-care workers linked to HAART delivery are particularly in favour of disclosure, as is expressed in the following quote from an adherence counsellor from Khayelitsha:

> What makes a person adherent … the first thing I would say is disclosure. If you have disclosed you don't have a problem, even if it's one person, and then you will take your meds properly, that person you have disclosed to or the treatment partner inside the house is going to remind them 'time to take your meds' or ' I noticed you were not taking it but just as a reminder', you've got the overwhelming support inside the house and you are stress- free, but if you did not disclose it is eating you inside, you are sensitive and if people suspect what you have, and then one other day you will take your meds and one another day, when people are here, you won't take your meds, and the stress will make you forget, whether I have taken my meds or not, and then the stress leads to depression and then you won't adhere, so disclosure is number 1, people who have disclosed they don't have a problem, people who live openly with their status they don't have a problem. (Interview with HIV Counsellor in Pienaar et al 2006: 44)

The situation of HIV-positive people changed for the better once the South African government started rolling out HAART in the public sector from 2004 (Nattrass, 2006c). The early guidelines stated that PLWH should receive treatment when their CD4 cell counts were less than 200cells/mm³, that is, when they typically had become AIDS-sick (Department of Health, 2004).[57] The introduction of HAART added an important dynamic to the disclosure situation. The patient's health on HAART increases dramatically over the first six months of treatment, with fewer opportunistic infections experienced (MSF et al, 2003; Coetzee, 2005). Importantly, patients' perceptions of their own health tracks improving clinical markers such as the CD4 cell count (Coetzee, 2005; Coetzee and Tasiran 2006). Disclosure may thus become gradually easier due to the psychological and physiological benefits of HAART (Klitzman et al, 2004), but the need to disclose for health-related support of course diminishes. In addition, HAART is now recommended when PLWH's CD4 count goes below 350. Therefore some patients may only experience minor Stage 4 symptoms. However, even if the need for illness-related support is minimal, disclosure is still recommended by healthcare professionals when starting HAART for drug adherence and retention purposes more than anything else.

From a social support perspective, during the first few months on HAART, health-care professionals in the clinic setting as well as community-based health-care workers provide intensive and continuous support for all patients on HAART. Patients are asked to identify 'treatment buddies' – that is, people who understand their needs as HAART patients and who will remind them to take their treatment regularly. HAART patients are also directed towards community organisations that can contribute or support household, food, financial and social security.

7.10 Nurturing important relationships

Of all of the participants in this study, none reported negative experiences of disclosure to their chosen household members (excluding sexual partners). In most cases where disclosure took place during an episode in which their health status was severely compromised, the support and care continued. Even when disclosure took place when the person was asymptomatic, the participants' significant others were typically encouraged to engage with the HIV/AIDS issue, learn more about it, and administer the care that was necessary to ensure the well-being of their loved ones.

[57] WHO guidelines state that PLWH should be put on HAART when CD4 counts dip beneath 350 cells/mm³ (WHO 2006)

The nature of relationships, with kin, household members and friends, is based on reciprocal obligations between parties. 'Trust' is an essential part of these obligations. After being looked after for so long by these significant others, the women felt a responsibility to tell them about their HIV status.

> Because they are the people that are close to me and they are the ones who were looking after me while I was sick, even though now they see that I am healthy. They need to know about what is happening and what has happened. (Nonceba)

Another woman, Ntombi, felt that the disclosure message ought to come from her. It would possibly be harmful to the relationship if her significant others found out about her HIV status through a third party thereby causing boundary turbulence.

> I don't care about the community, but I feel I will not be alright when I [don't] tell you and then somebody [else] says, 'Oh Ntombi you are HIV-positive. [X] told me.' I will not feel all right. (Ntombi)

For Sylvia, she did not want to be treated differently.

> …they make me very upset and they always buy everything at home for me. I say, "What you are going to eat, I am going to eat. I am not a separate person who must eat this and who mustn't eat that. I eat everything but I must limit myself from the other things, like alcohol, like sweet things". (Sylvia)

She stressed the fact that her relationships with her significant others should remain the same although she was HIV-positive. Her disclosure was also an opportunity for her to educate her significant others about the needs of HIV-positive people.

7.11 Educating others

Educating significant others was an important reason for disclosure amongst a number of the research participants. This was especially the case amongst those participants who had never

experienced serious opportunistic infections and who were diagnosed while pregnant. This may be attributed to the fact that they were activists, wanting to change popular misunderstanding of HIV/AIDS in Khayelitsha, or wanting to protect their loved ones from possible infection. However, it is plausible to assume that because of their HIV infection and experiences of HAART or PMTCT the women are 'experts' and therefore can protect their loved-ones through education based on real life experience. Zoliswa and Zameka disclosed to particular family members due to such concerns.

Zoliswa disclosed to her younger brother as she wanted to educate him regarding prevention. This method of disclosure was also a method of testing her brother's reaction to issues surrounding HIV/AIDS. Interestingly, her brother responded by reassuring her and observing that she should not feel stressed because HIV was 'all over the world' – i.e. was a common occurrence and that she should not feel socially isolated. His first reaction, in other words was to reassure her of his support and to reduce any fears she may still have about AIDS stigma.

> So I educate my brother, my youngest brother. He is 22. I educate him first … Firstly, I teach him about the condom, he must use condom every time because there is a virus outside … He understood, and another time I asked him: 'If I told you that I am HIV-positive, what will you do?' He said, 'Oh, no problem because you are my sister. I can help you if maybe you need money, maybe to buy some medicines, or if you are sick I can hire the transport to go with you to the clinic, I don't have a problem.' … And then I told him that I am HIV-positive. He was crying a lot, but he told me, 'No problem. I am here for you, no problem. If you have a problem, tell me. I am going to help you. I am working, no problem, we are together now, don't be stressed about this because you are HIV, it's all over the world.' (Zoliswa)

When Zameka found out that her father was having multiple sexual partners, she felt the need to educate her mother so that she would take the necessary precaution. Dunyiswa disclosed to her ex-boyfriend so that she could challenge his negative perceptions of PLWH.

> He used to badmouth PLWH, so I hated that, so I decided to disclose to him. (Dunyiswa)

Dunyiswa's disclosure was not so much about providing facts about HIV/AIDS, but more along the lines of challenging his attitude towards HIV/AIDS. It was extremely brave of her to do so, considering the risk of knowing he had these negative perceptions. It seems that she felt the need

to challenge his negative perceptions by locating herself amongst them, that is, how could he stigmatise other PLWH when he was in love with someone who was HIV-positive and accepted her? Dunyiswa went on to say that this man left her after finding out her HIV-status, and blamed her for bringing HIV into their relationship. Although Dunyiswa had not disclosed to her siblings, she expressed the desire to do so in order that they can learn from her.

> All I want, I want to help my family. I don't want to my sister or my brother to be HIV-positive. (Dunyiswa)

Disclosing to your family is seen to be preventative in that you can educate them and serve as a role model for discouraging them from contracting the virus. In these situations, the women are empowered by their 'expert' knowledge of HIV/AIDS. Educating loved ones about prevention and HIV/AIDS in general is an important contribution that the women can make towards their families, within other important non-family relationships and towards changing popular misunderstandings of HIV/AIDS in their communities.

7.12 Maintaining psychological well-being

For many women, in the time following their diagnosis, they felt unable to disclose not only because they feared rejection, but also because they were struggling themselves to come to terms with being HIV-positive. Some of the women talked about a process of coming to accept themselves and their status. This process transformed the way they felt about being HIV-positive which led them to feeling increasingly able to disclose. While some of the women continued to disclose very selectively and to relatively few people, others said that they began to 'feel free' to disclose more openly. In fact, many of the women drew on this notion of 'being' or 'feeling free' with their status as an important indicator of having overcome many distressing aspects of their diagnosis. For these women disclosing meant 'to be free' – free of fear and guilt – and they felt that by sharing their secret, they no longer needed to be burdened by it.

> …the meaning of disclosure for me is to take out the thing that is inside of your heart and to tell another person, yes. The feeling of that is I can say it's a medicine for myself because when I talk to someone it's like I drink some medicine and get cured, yes. (Zoliswa)

> Because sometimes if you didn't disclose and you have a lot of stress and you thinking you alone in that time. So if you disclose to someone, you share your problem. (Bulelewa)

Sylvia discussed the long period of time between her diagnosis and the disclosure to some of her significant others. She thought that her disclosing would put too much stress on her household, specifically her aging mother. However, she did tell her family in the Eastern Cape (including her mother) four years after her diagnosis. She describes this as a very positive experience.

> It feels better because you know that the pain, the pain is gone now … Something like you are carrying a sick baby, you don't know when it's going to get better. But when you found out you did disclose that baby is feeling better now - it's all right like the other babies. (Sylvia)

This explanation is particularly poignant as a few years previously Sylvia lost a young child. Interestingly, she articulates her newer, less stressful position, using a health metaphor. The health metaphor is common to many of the women's responses. They speak about disclosure as a form of medicine – the secret to curing the 'sick baby'. For some women in this group, HAART is a treatment for the HIV-infected body, while disclosure is a treatment for the 'HIV-infected mind'.

7.13 Discussion

Two key themes are evident in the narratives of disclosure to significant others: disclosure in order to access health-related support; and disclosure in order to educate significant others. It is important to note that all motivations occurred within specific relational contexts and were mediated by the dynamics of these relationships.

For many PLWH, disclosure is the means to access health-related support and services to manage their illness. Despite the very real fear of stigma (as evidenced by the women's narratives), the data from this study suggests that this fear may be based on unfounded perceptions as none of the participants have experienced traumatic events as a result of being identified as HIV-positive when they disclosed to carefully selected household members (excluding sexual partners which is discussed in Chapter 8). Disclosure during the symptomatic phase resulted in positive responses from significant others, which led to assistance in accessing appropriate health-related support,

while disclosure during asymptomatic periods led to expected emotional support. However, we do not know whether this particular group of women were in more supportive environments to begin with than other PLWH – so caution must be exercised in drawing strong conclusions from this qualitative part of the study about the general environment facing PLWH in Khayelitsha.

In six of the eleven cases in this study, disclosure occurred during stage 3 or stage 4 of HIV disease, that is, when their immune systems were severely compromised and there were experiencing serious opportunistic infections. This does not necessarily indicate that the participants delayed their disclosure due to fears of the reaction, but rather they were at these late stages when they were diagnosed and hence needed immediate support. Alonzo and Reynolds (1995) attribute this to the fact that the person is no longer able to hide his or her status as the disease becomes clearly visible, and treatment, care and support become necessary for survival. The biophysical effect on disclosure is evident in other studies where disclosure patterns varied according to psychological conditions, fear of stigma and stage of the disease (Holt et al, 1998).

The specific form of support required by the PLWH plays an important role in the disclosure process. Some participants chose to disclose so that their significant others would know the appropriate treatment for diseases and symptoms caused by HIV and a compromised immune system. This included a desire not to be taken to traditional healers because they thought that traditional medicines would do more harm than good. As noted earlier, anecdotal evidence from PLWH suggests that health-professionals in clinical settings discourage the use of traditional medicine (Wreford, 2005; Mall, 2005). It is possible that PLWH use traditional medicine more often than they admit, but deny using them because they have been told not to (ibid.).[58] However, their experience with HAART, together with MSF and TAC education, appears to have encouraged them to use a healing system with 'proven' results. This was reflected in the reasons for disclosure described by the research participants.

In five cases, the participants were healthy at the time of disclosure. In these cases diagnosis occurred during pregnancy, rendering them eligible for the PMTCT program. In four of these five cases, the primary motivation for disclosure was based on educating others about HIV from both social and biological perspectives. This is consistent with a study of 322 HIV-positive African-American women, where content analysis highlighted motivations that included a desire to increase awareness around HIV/AIDS and to overcome AIDS-related stigma through disclosure

[58] See 'Small clinic at centre of debate over traditional medicine' http://www.irinnews.org/S_report.asp?ReportID=53090&SelectRegion=Southern_Africa accessed 7/05/06.

of their HIV-status to significant others (Sowell et al, 2003). Similarly, in a qualitative study in two South African communities, Norman et al (2005) found that that disclosure was used as an opportunity to educate significant others and challenge HIV/AIDS stigma.

When the participants' health was not compromised, they had no need for health-related social support. The stories of Buyiswa and Sylvia give weight to this suggestion as both were diagnosed while pregnant but had never experienced serious opportunistic infections. Although the timings of their disclosures were substantially different, both disclosed to their families, at carefully selected times, as a way of nurturing good familial relationships, receiving emotional support, and educating their significant others about HIV/AIDS. Another four participants that were diagnosed while pregnant disclosed some time after their diagnosis (between nine months and two years). Medley et al (2004) showed similar findings where rates of disclosure in developing countries were lowest when the person was diagnosed while pregnant.

For those participants that had experienced serious symptomatic phases and had been cared for by significant others, they expressed similar feelings about wanting to disclose in order to nurture these important relationships as well as being loyal to these care-providers. There seemed to be a number of reasons for this. Firstly, they felt a responsibility to disclose to specific significant others as these were their carers when they were sick i.e. it would be unreasonable or unfair to keep this secret from them. Derlega et al also found that loyalty in close relationships was a crucial factor in the disclosure process (1998; 2004) and that loyalty to family members outweighed loyalty to partners and friends. From a risk/benefit perspective, the risks of negative consequences were low considering that these significant others had already invested substantial time and resources in giving support to one of their sick loved ones. Secondly, they did not want their significant others to hear of their HIV-positive status from a third party thereby causing 'privacy boundary turbulence' and aggravating an already sensitive situation where some of the women had been keeping their diagnosis secret for some time.

The degree to which people cope with the physical and psychosocial aspects of living with HIV/AIDS is to a large extent affected by disclosure decisions (Schmidt and Goggin, 2002; Holt et al, 1998; Petrak et al, 2001). Poor emotional well-being, including depression and HIV–related anxiety, has been attributed to lack of satisfaction of social support due to non-disclosure (Armistead et al, 1999). Numerous studies have demonstrated the positive psychological benefits of disclosure, where revealing secret information to significant others is at first stressful, but consequently cathartic (Brandt, 2005; Armistead et al, 1999). Furthermore, Strachan et al (2007)

found that patients' CD4 count was independently predicted by disclosure of HIV status and sexual orientation after controlling for bio-behavioural covariates in a sample of MSM in the USA, therefore demonstrating the potential health benefits of disclosure.

From both relational and educational perspectives, many participants felt a need to counter perceptions of morbidity and mortality when disclosing to significant others through challenging the false perceptions that one must be and look sick to have HIV; and to educate others that HIV is a chronic manageable illness and not a death sentence. Some studies suggest that PLWH worry that those they disclose to will think they are dying and that this will be a very painful experience for everybody involved (see Greene et al, 2003). In fact, in this study, some respondents' suspicions were confirmed by the reactions of their significant others when they disclosed their HIV status (as in the cases of Sylvia, Lizeka and Nonceba). Sylvia spoke about how those she disclosed to reacted as if her death was imminent although she was not yet on HAART due to her excellent health. She wanted to be treated as normal when she disclosed, and therefore aimed to educate others regarding her situation in terms of her HIV-status (i.e. that she was HIV-positive but not ill and could thus go about her daily life in a normal manner). These findings are consistent with other international studies where PLWH do not want to be a burden on others (Holt et al, 1998). They desire to be perceived as contributing members to their respective households and society.

At certain times and under certain circumstances, it is necessary to engage with significant others or friends for support, but at other times, it is also necessary not to burden others and hence risk beneficial and supportive relationships. In a study of disclosure in South India, Chandra et al (2003) attributed the higher rates of disclosure to family members as opposed to non-family members to the notion that the family is the primary support system in India. Similarly, O'Brien et al (2003) found in a diverse sample of 269 HIV-positive people in New Orleans, USA, that people in advanced stages of HIV preferred to draw upon the support of close family members as opposed to outsiders (69.8% of respondents disclosed to immediate family members as opposed to 27% to other relatives and 26.4% to friends). In this study, participants generally balanced the potential negative consequences and risks of disclosing with the potential support given particular relational histories and qualities. They then disclosed to the people they trusted most and could foresee minimal negative consequences in these valuable relationships. This suggests that HIV-positive people may feel distanced from general society and more dependent on significant others as their illness progresses and they experience more severe opportunistic infections.

As discussed in Chapter 3, the impact of disease progression on HIV status disclosure has been recognised (Holt et al, 1998; Alonzo and Reynolds, 1995; Strachan et al 2007). The individual's health situation at the times of diagnosis and disclosure, in addition to the impact of this changing health status on the social context in which PLWH live, have been underreported and understudied in the South African context. This theme was clear in all the qualitative interviews and during the focus group discussions and the link between health status and experiences of stigma (gossip in particular) was also demonstrated in the quantitative analysis in Chapter 5. So, while CPM theory provides a useful theoretical framework for understanding the individual decision making process, and Ulrich Beck and Anthony Gidden's risk society approach enables a more nuanced understanding of the social context in which people make these decisions, the key elements of the stigma trajectory thesis enable a dynamic understanding of the ways in which individual and social processes interact with the changing nature of HIV disease over time.

The chapter has also suggests that PLWH, especially in Khayelitsha, are extremely knowledgeable about HIV disease and the ways in which HAART and PMTCT works on the body, including the negative interaction between HAART and traditional medicine. However, the individual making these decisions exists within a socio-cultural context characterised by misguided and stigmatising perceptions of HIV/AIDS. Consequently, the motivations for disclosure and the choice of recipients are based on a complex and subjective combination of countering false popular perceptions of HIV/AIDS, and accessing appropriate treatment, care and support. Through the lens of disclosure, it is clear that HIV/AIDS must viewed as a dynamic and changing bio-psychosocial experience in which disclosure is both a response to, and in turn shapes, the social world of PLWH.

Chapter 8: What are the dynamics of disclosure to sexual partners? A qualitative analysis

The biggest challenge facing HIV prevention programmes within sexually driven HIV epidemics is how to bring about sustained changes in sexual behaviour. Behaviour modification is an essential aspect of large-scale prevention and treatment programmes world-wide (UNAIDS 2010) and HIV disclosure both publicly and within sexual relationships is a key mechanism in bringing about such change. People who are HIV-negative are educated and counselled to practice safe sex and people already living with HIV are counselled to practice safe sex so as to protect their sexual partners and to protect themselves from becoming re-infected (infected with new strains of HIV). The importance of prevention within relationships has gained traction in recent years as research in sub-Saharan Africa has shown that up to 50% of PLWH in stable relationships have an un-infected partner (Guthrie et al 2007). Further, recent prevention campaigns have also included a drive to reduce multiple concurrent partners (Mah & Halperin 2010). Beyond this, understanding condom use and sexual behaviour is a crucial aspect of modelling the impact of treatment technologies such as HAART and PMTCT on the course of the epidemic. For example, Nattrass (2007) used the ASSA 2003 AIDS-demographic modelling package for South Africa to show that if there is 100% increase in uptake of VCT as a result of HAART, new infections will be reduced, but if condom use in the general population declines by 10% due to HAART-related disinhibition, the positive impact will be negated.

Importantly, research over the past few years has pointed to HAART as a possible prevention[59] technology (the so-called 'test and treat' agenda) which has gained traction in global HIV debates (Difenbach and Fauchi 2009; Granich et al 2009) leading to new recommendations made by WHO in 2011 for couples testing and early initiation of treatment discordant couples (where one partner in HIV-positive). The landmark HPTN052 clinical trial, with 1,763 discordant couples in 13 sites in nine countries, showed that early initiation of HAART for the infected partner in a discordant couple reduced transmission rates by 97% (Cohen et al 2011). In other words, if a person is on HAART and their HIV viral load is suppressed, they have a much lower likelihood of transmitting HIV to their partner. The modelling further shows that the epidemic could be eliminated after 10 years (through reducing transmission to one new

[59] ARVs for the prevention of mother-to-child transmission of HIV is a universally adopted intervention.

infection in 1,000 PLWH) if all PLWH were identified and treated with HAART (ibid.). For 'test and treat' to work in discordant couples, the need for disclosure and open discussion about HIV within these couples cannot be overstated.

Most prevention strategies in sub-Saharan Africa have adopted the ABC ('**A**bstain, **B**e faithful, **C**ondomise') approach.[60] However, this simplistic (and rather jingoistic) approach fails to take into account important relationship dynamics or the challenges this poses for decision-making and vulnerability. For example, if one of the partners in a sexual relationship has unprotected sex outside the relationship and fails to disclose this to his or her regular partner, then no matter how 'faithful' the regular partner is, he or she will still be exposed to the virus. ABC is, as Venter puts it, "a message that has little protection value for those in marriages where one partner may bring HIV infection home" (Venter 2006:300).

The simple message 'use condoms' also has its limitations once relationship dynamics are taken into account. Couples may choose not to use condoms in order to have children – a decision made easier since the advent of HAART (Ndlovu 2009; Meursing 1997). They may also grow weary of using condoms and desire to stop using them as a signifier of emerging trust and intimacy in the relationship (Harrison and Sullivan 2010:997). US-based research (with gay and bisexual men, and IDUs) has shown that couples may choose to move from condom-use to unsafe sex as the relationship strengthens and develops (Katz et al 2000; Misovich, Fisher and Fisher 1997).[61] South African research on condom use indicates a similar impact relationship dynamics; because condom use signifies casual relationships, there is pressure on both parties to longer-term relationships to demonstrate growing trust and intimacy by discarding condoms (Bermudes and de Cruz, 2004). Little work has been done, however, in South Africa on condom use and disclosure in partnerships where at least one of the partners is HIV-positive. US-based research also suggests that condom use may fall over time if PLWH perceive themselves to be less infectious due to the benefits (in terms of lower viral load and hence infectiousness) of being on HAART (Kalichman et al 1998). For example, Sullivan et al (2007) found that 15% of HIV-negative or untested MSM in their sample in the US reported treatment-optimism related risk behaviour. The limited available research from South Africa, however, suggests that this particular motivation for unsafe sex is not evident because PLWH remain concerned about re-infecting themselves through unsafe sex (Leonhardson, 2007).

[60] The counselling (C) in VCT most often is based on ABC.
[61] See Misovich, Fisher and Fisher (1997) for a comprehensive review of US-based studies looking at sexual behaviour within minority and non-minority heterosexual relationships, injecting drug users, and men who have sex with men.

In short, we need to understand a lot more about the relationship dynamics and social understandings which underpin condom use if prevention interventions are to be made more effective. The ABC approach fails to account for gender differences (in terms of relationship power and vulnerability), relationship characteristics (especially trust, risk and honesty) and the changing dynamics of specific relationships over time that pose challenges to ongoing condom use. It also fails to consider the ways in which these relationship dynamics influence the decision taken by HIV-positive people to disclose their status to sexual partners.

In modelling the potential impact of disclosure on prevention of sexual transmission of HIV in the US, Pinkerton and Galletly (2007) showed that, depending on the proportion of partners who agree to sexual intercourse after disclosure, disclosure can lead to a 17.9% - 64.1% reduction in risk of HIV transmission compared to those not disclosing (ibid. 702). Whereas evidence from the US is mixed and shows instances where disclosure may lead to both reduced risk taking (Bird, Fingerhut, McKirnon 2011; Sullivan 2005) and increased risk taking (Kalichman and Nachimson 1999, Sheon and Crosby 2004), the evidence from South Africa seems to suggest that where disclosure occurs in sexual relationships there is an increased likelihood of safer sexual practices (Olley et al 2004; Wong et al 2009). Olley et al (2004) found that, amongst HIV-positive men in South Africa, non-disclosure was correlated to a higher likelihood of unsafe sexual practices including no condom use at last sexual encounter, heavy alcohol use before sex, and multiple sex partners. Wong et al found that in their sample of 217 PLWH in urban and rural South Africa, those who eventually disclosed to their partners were more likely to use condoms and reduce their number of sexual partners (2009: 219).

International studies indicate that disclosure rates to intimate partners vary widely. In their meta-analysis of 17 studies of disclosure amongst women attending prevention of mother to child transmission (PMTCT) services in developing countries, 15 of which were in sub-Saharan Africa, Medley et al (2004) found disclosure rates ranging from 17% to 86%. More recent studies, such as ANRS-EVAL Study in Cameroon, found that 86% of women disclosed to their most recent sexual partner (Loubiere et al 2009). Studies from the US (mostly focussing on MSM and IDUs) find higher levels of disclosure to intimate partners than to family members or friends (Serovich et al 2005; Simoni et al 1995). Mansergh et al found that 73% of their sample of HIV positive MSM had disclosed to their lovers while only 30% had disclosed to their mother, and 5% to their father (Mansergh *et al.* 1995). Simoni *et al.* (1995) found relatively low rates of disclosure to extended family members, somewhat higher rates for

immediate family members and highest rates for lovers and friends. It is important to point out that these US-based studies may be reflective of a homosexual-driven epidemic rather than the heterosexually which is the dominant mode of transmission in Africa.

South African research also suggests diverse findings. Makin et al (2008) followed the same group of HIV-positive women in Soweto over time and found that rates of disclosure to sexual partners increased from 59% in 2003 to 67% in 2004. On the other hand, Simbayi et al (2007) found in their study of 1,054 people living with HIV in Cape Town, of which 50% were on HAART, 42% (n=378) of sexual active participants had sex with a person to whom they had not disclosed their HIV status in the previous 3 months. In a study of a community sample from Vulindela in KZN and Soweto, Wong et al (2009) also found relatively low levels of disclosure to casual sexual partners where 59% of their sample of 217 PLWH disclosed to their spouses while only 14% of the sample disclosed to casual sexual partners.

In many of these studies, PLWH continue to report fears of blame, violence and abandonment as prohibiting full disclosure to sexual partners. And, while these fears are legitimate and often based not only on perceptions but on continuing stigmatizing attitudes in the general population (Maughan-Brown 2008), consequences are often less severe than anticipated. For pregnant women in South Africa, Varga et al (2006) found that voluntary disclosure ultimately resulted in a supportive, constructive response (74.2%), after some partners' (27%) initial upset, anger or rejection. In Medley et al.'s (2004) review of disclosure, they found that while 4-28% of women reported negative consequences of disclosure, many respondents (19-73%) reported positive outcomes such as kindness, understanding and acceptance after disclosure. However, they also found that 3.5% - 14.6% of HIV-infected women reported experiencing a violent reaction from their partner following disclosure (Medley et al 2004). Accordingly, disclosure within sexual relationships is a more important, and in many senses, a riskier decision than disclosure to other people (Grinstead et al 2001; Gielen et al 2000), but the evidence continues to demonstrate a range of experiences.

Thus, despite high rates of disclosure to sexual partners and high levels of positive responses, even few instances of negative reactions are highly problematic. Stories about negative disclosure experiences could result in HIV positive people believing that there is a lot of stigma in the general population (which in turn deters people from disclosing) or direct experiences of negative consequences following disclosure can deter people from disclosing to others in the future (Maman et al 2004; Sigxaxhe and Matthews 2000).

The decision to disclose to a sexual partner (or potential sexual partner) is profoundly structured by the nature and strength of the intimate relationship, perceptions about sexual relationships in general (particularly pertaining to trust) and understandings of the costs and benefits of disclosure. These, in turn, are a product of social norms and individual experiences. Understanding disclosure thus requires an understanding of the social norms (gender most importantly), lived experiences and perceptions of the nature and value of sexual relationships of the people concerned.

This chapter makes a contribution to filling the gaps in our knowledge about HIV disclosure and condom-use in sexual relationships where at least one partner is HIV-positive. Using qualitative methods with the same group of HIV-positive women analysed in the previous chapters, it explores disclosure in terms of the important contextual issue of the nature of the sexual relationship and its changes over time.

The analysis begins by describing the participants' accounts of past relationships with men and their consequent negative perceptions of men and cynical attitudes towards sexual relationships in general. Nevertheless, emerging through some of these narratives is the hope expressed by many that a 'good' man can be found and that not all relationships are necessarily going to end badly. This juxtaposition of cynicism towards men and 'romantic' hopes about relationships has been described by Hunter (2004) in the context of an ethnographic study in Kwazulu-Natal, South Africa. The evidence presented here indicates that similar romantic hopes are harboured by some of the women, although the majority are cynical and distrusting. This may well be because they have more to lose from trusting a man (as he could tell other people about their HIV status). The chapter then moves on to describe the participants' attitudes towards disclosure to sexual partners, specifically in relation to deciding on and negotiating new relationships. Those who are entirely cynical and distrusting of men recommend not disclosing (or at least only disclosing later on in the relationship) or even not having sexual relationships at all. Those who harbour 'romantic' hopes about men recommend disclosure up front as a 'test' of the potential relationship which although exposing the individual to rejection, brings with it great potential benefits in terms of relationship trust and intimacy.

The chapter then moves on to discuss the different types of relationships experienced by the participants and the dynamics of disclosure and condom negotiation within these relationships. A key finding is that length of relationship matters, although this has its own stresses. Those women who argue that disclosure should only take place once the relationship has proved itself

over time, find themselves in a tricky position of having to disclose their HIV status to a man who might (understandably!) have wanted to know about it earlier. The very act of delaying the disclosure because the women did not trust the men thus has the potential to expose them to censure and retribution from men for this dishonesty. Those in violent relationships may thus never disclose to their sexual partners, and when it becomes difficult to continue to negotiate condom use, end up having unprotected sex. Table 8.2, below summarises some of these key factors relating to the women's experiences of relationships, and also notes who is on HAART or has experienced physical manifestations of HIV/AIDS.

Table 8.2: Summary disclosure details of participants

Name	**HAART or not plus other distinguishing features**	**Attitudes to disclosure**
	Untrusting	
Ntombi	On HAART	Does not trust men, but feels that disclosure is necessary – and so has decided not to have relationships at all. Has chosen to remain single
Lizeka	On HAART	Says that it is better to disclose and risk rejection – but that you don't have to do it immediately if you use condoms
Nonceba	On HAART	Does not trust men in general (e.g. has not disclosed to her father). But has had mixed experiences of disclosure, as has had many relationships. She refers to Zoliswa and Dunyiswa who have been rejected after their disclosure and does not want this to happen to her. She says that she sees the importance of disclosure, but would only do so if she loves the man.
Buyiswa	Not on HAART	Says you must disclose, doesn't do it immediately (but uses condoms) and has had bad experiences with men leaving her (for HIV-related and unrelated reasons). Feels guilt and ambivalence – is in the process of disclosing. Uses condoms all the time so doesn't fear blame
	Romantics – early disclosure	
Liziwe	On HAART Has HIV scars	Agrees that early disclosure can help build trust. Says it is better to disclose and risk rejection.
Thembi	On HAART Has HIV scars	Has had bad experiences. Says it is not worth seeking men out – but is still hopeful of a good man. Strongly favours early disclosure to build trust and intimacy. Discloses all the time
Zoliswa	Not on HAART Has HIV scars.	Risks and stress of relationships are not worth actively seeking out a man (particularly hassles involved getting men to use condoms). Says one should be patient (finding a good man is possible, but it is a matter of divine providence). Agrees that early disclosure can help build trust. She had a good experience of early disclosure, but he left her. She found another partner who was found guilty of murdering her.
	Established relationships	
Dunyiswa	Not on HAART	In an established relationship (prior to and subsequent to her diagnosis). Did not disclose, but the partner found out by chance.
Sylvia	Not on HAART	Involved with the same man before discovering she was HIV+. Has not disclosed. Uses condoms, but not all the time.
Zameka	Not on HAART	Knew she was HIV positive before becoming involved with the man she subsequently married. Does not use condoms. Has not disclosed – does not use condoms

8.1 Context of relationships and perceptions of men

Individual interviews and focus group discussions revealed that most of the women had experienced unhappy relationships with men – both as a consequence of, but also independent of their HIV-status. Ten of the eleven women reported that the fathers of their children had left them (in some cases more than once). At the time of the interviews, two of the women admitted to being abused by their boyfriends to the extent that they laid criminal charges and needed medical treatment. Tragically, Zoliswa was murdered in early January 2007 by her husband. It is within this precarious social position that these women decide whether they want new relationships, cope within established relationships, and negotiate disclosure and safer sex.

It is also useful to distinguish between the challenges for disclosure in new relationships, and in established relationships. All of the women were cynical about men in general. However, with regard to new relationships, two different approaches can be identified: those who were so negative about men and the possibility of having trusting and emotionally fulfilling relationships that they were wary of having relationships with men altogether, and those who despite sharing the generally cynical approach to men, were nevertheless hopeful of finding a "good" one. Attitudes towards disclosure in established relationships are more complex, and are discussed separately.

8.2 Negative attitudes towards new sexual relationships, and fears of disclosure

With the exception Zameka, who was involved with the same partner from the time she discovered she was HIV-positive, all the research participants spoke openly about the challenges of negotiating new sexual relationships (hereafter simply referred to as a 'relationship').

The majority of the women have had more than one partner since HIV diagnosis, and most have experienced both positive and negative reactions to their disclosure. A general theme that emerged from all accounts is the perception that disclosure is very risky. This perception draws from actual past experiences, the stories they have heard from each other within the group, and

the experiences of other women in the wider community.[62] It appears that their sexual experiences prior to HIV diagnoses had already given them reason to be wary of men – and that being HIV-positive simply compounded the problem of building trust, negotiating condom use and disclosing their HIV status. In a social context that spawns generally fraught and fragile relationships, the women realise that something like HIV is certainly a good enough reason for men to leave them or not to begin a relationship in the first place. HIV therefore poses immediate and future risks in terms of stable relationship building.

Some of the women, such as Zoliswa and Ntombi, had therefore chosen not get into relationships and were single at the time of the interviews. Zoliswa stated that the risks and complexities of relationships are not worth the stress and that finding a 'decent' man is a matter of divine providence.

> It is nice to have a boyfriend, but I can say maybe [you need to be] lucky. So you must wait and see. [At] the right time you are going to have someone. You mustn't rush. You must wait. Maybe God is going to give you the better one (Zoliswa)

Men have always disappointed Zoliswa (both the fathers of her children left her to care for the children on her own) and the man she subsequently married killed her. Yet during the interviews she argued that she needed to be patient especially now that the difficulties of disclosure and condom-use are core features of new relationships. As she said: "And you can't disclose [to] all of the people that you meet. But if he doesn't want to use condoms, you must disclose. If he wants to leave he must leave, if he wants to stay, he must stay." She pointed out that life and relationships are more difficult in the age of HIV and STDs: "Because now there is HIV and STDs and our boyfriends are not faithful. They don't want to use condoms. So I decide to stay [alone]." Zoliswa had therefore decided to remain single, and to concentrate her energies on looking after her children. She said that men bring a lot of stress into her life, with constant worrying over where they are, what they are doing, why they have not phoned etc. She therefore believed that it is easier to stay alone than to risk being hurt by men.

> I am not ready, maybe when times goes on … Now I want to continue with my children. Because if I think about the boyfriend, the boyfriend does a lot of things and

[62] During my observation of the women facilitating HIV support groups, I often heard similar accounts of women who had experienced huge challenges disclosing to sexual partners.

> you get stressed if he doesn't phone you, doesn't come to you, a lot of bad things. So if I am staying alone with my children at home, I don't have a problem. (Zoliswa)

Similarly, Thembi felt that her efforts should be focussed elsewhere. Her experience with a previous boyfriend (who was also HIV positive, and whom she subsequently had a child with), whom she suspected of being unfaithful, illustrates this point.

> And I sort of say: "Okay if you just coming in and going out, just leave." Because he was like making up stories and saying that his old girlfriend came by his house and he couldn't go out and all [those] things. And I said, 'Okay, stay with your old girlfriend and leave me alone. I will do the things that I need to do, even if I have no boyfriend." [I] just accepted that, maybe someone will come. It doesn't matter if have a boyfriend or not. That is not important now. What is important is my health at the moment [and] just spending most of the time with my family, my sisters. (Thembi)

Ntombi, however, was not willing to risk the consequences of disclosure posed by her lack of trust in men. She therefore chose not to get into a relationship.

> Me, I am not ready to go and disclose with a boyfriend. That's why I am not ready to jol.[63] I am alone now. From 2002 I am alone, I have no boyfriend because I am not ready to tell every Jack and Jason, to tell him now about my status. (Ntombi)

Fears of disclosure at the beginning of relationships (and hence fear of beginning new relationships in general) are seemingly based on three core perceptions: fears of rejection; fears of boundary turbulence; and men's apathetic attitude towards condom-use. The fear of rejection (because of their HIV status) is a constant theme in all the interviews. It generates a lot of anxiety, especially when the women are unsure whether it was their HIV status or other factors which destroyed past relationships. The following comment from Buyiswa expresses the guilt, fear, ambivalence and doubt very clearly:

> I am always disclosing to many boyfriends that I have since last year. I think about three or four. So I get the feeling like what if, because I don't keep them, I am not that type of women that really sticks with one person? So I am always saying what is, like how many boyfriends will I end up? Because sometimes I know it is not my fault,

[63] 'Jol' is a colloquial term for going out to bars, nightclubs or parties etc.

> sometimes it is their fault … But then again I don't think it can last, even with the one I just had for two months now. I don't think it will last because even last week I went to him wearing my HIV positive T-shirt, so I am starting to disclose because it is eating me inside. I know it is not really good. So I don't think it will be long. So I am not really a very good person to keep secret even though I get this, I feel it. (Buyiswa)

Buyiswa's fears are seemingly related to issues of self-worth. She is not too concerned about men's reactions based on her HIV-positive status, as she insists on always using condoms. Thus, she cannot be blamed for putting the men at risk of infection. Many of the other women's fears are based more on cynical perceptions of men and relationships. The following statement from Dunyiswa exemplifies such perceptions.

> If you disclose, he runs away.... He runs away from you because you are HIV positive. Maybe you are not sick, [but] you are very cute and you are beautiful, but he runs away. (Dunyiswa)

A general lack of trust in men, especially at the beginning of a relationship, emerged from the narratives as a key constraint to disclosure. The women do not know the man well enough (by virtue of it being the beginning of a fragile relationship) to be telling him their HIV secret and hence risking the possibility of him telling others – a reference to the fear boundary turbulence and potential stigmatisation as a result of unintended persons finding out about their HIV-positive status. Stigmatisation may include gossip (see Chapters 5 and 6) but may also result in previous partners who were not disclosed to finding out their HIV status – a potentially life threatening situation if condom use was inconsistent in that previous relationship.

Dunyiswa and Ntombi perceived men to be a 'risk group' in terms of maintaining a privacy boundary around their HIV secret. This affects their initial desire to get into a relationship due to the perception that it is highly unlikely that their HIV status will remain confidential. In her interview, Ntombi expressed fears of boundary turbulence due to disclosure to third parties without one's permission: "when you go to tell him, he run away and he go to tell another people, you see. So I don't want to disclose with a boyfriend." Dunyiswa was similarly fearful:

> It's difficult because so many people know me in Khayelitsha … (The) father of my child was not my first boyfriend. Maybe they are going to the ex-boyfriend to tell him,

> "Your girlfriend is HIV positive, then you are HIV positive." Maybe he really has got the HIV, maybe he didn't get it from me, [but] he is going to blame me. (Dunyiswa)

Buyiswa acknowledged that her activist involvement – which has resulted in her disclosing to 'the public' on numerous occasions – has probably made it impossible to control the flow of information about her HIV status:

> I am worried if I can get somebody that can be that cruel. Like somebody that will look for every man that I have had and say: "This one is HIV [positive]". And I always get the feeling that because I am disclosing to the public and everywhere, almost everyone knows. (Buyiswa)

As discussed in Chapter 6, the problem with public disclosure – or simply widespread knowledge about one's HIV status – is that it can become a defining feature of one's social identity and structures individual relationships, including intimate relationships. This represents a profound loss of control. It is often this, rather than some unfocussed fear of 'stigma' which seems to worry the women the most.

The third core perception that influences their decision to disclose has to do with men's attitudes towards condom-use. If disclosure is undertaken mainly to ensure condom-use, then the fact that men, especially Xhosa men, are perceived as not wanting to use condoms, is in itself a factor discouraging the women from beginning new sexual relationships. When asked about the mens' attitudes towards condom-use, Dunyiswa stated:

> Say I meet the boyfriend today, maybe he wants to sleep with me. If I say, "We must use the condoms." He says, "No. I can't eat the sweetie in the paper." So they don't care about HIV. (Dunyiswa)

Many in the group commonly refer to men's behaviour as being highly predictable, especially when it comes to condoms. As Ntombi stated about Xhosa men:

> Especially these Xhosa men, they don't want the condom. They have a problem. These Xhosa guys, they have a problem. The foreigners they are very understanding, they are not Xhosas. [64] (Ntombi)

8.3 A recognition that disclosure can be constructive of good relationships

Despite such negative perceptions of men and relationships, many of the group see the benefits of disclosure and some actively seek them out. Disclosure is seen as both an instrumental and intimate act, and in both such acts the women take risks in order to benefit. By instrumental, it serves the practical purpose of encouraging condom-use, or accessing social support. In terms of intimacy, disclosure is risky, but if successful, can help build trust and strengthen the relationship.

The women are also wary of being reinfected with HIV. This is the main reason why many of the women insist on condom use. As Zoliswa put it: 'I don't know if his HIV is stronger than mine'. They also do not want to transmit the virus to a new or existing sexual partner (although when men refuse to wear condoms or go for VCT, some of the women report losing sympathy with them on this score). All the individuals in the group are well educated about HIV/AIDS and they understand the physiological aspects of transmission, re-infection and disease progression. The reasons most the women give for disclosing to partners therefore tend to reflect practical and physiological concerns rather than emotional sharing. This discourse is different to the western model of truth telling as a form of catharsis and/or romantic/emotional sharing between people. In US- based research, Derlega et al (2000) found that the duty to inform and educate the intimate partner was the most important influence on disclosure for the respondents in their sample. Another study in the US with 174 PLWH of all ages found that catharsis was the most important factor in disclosure (Levy et al 1999). In this study, the women most often reported disclosing to their sexual partners in order to get the man to use a condom (to prevent infection and re-infection). According to Ntombi:

> It is very important [to disclose] because some of our boyfriends, especially black boyfriends, they didn't want to use a condom. They are very stubborn to use a condom. So it's better you must disclose and then you must go take it or leave it

[64] Ntombi refers to "foreigners" in this quote. She was referring to Buyiswa's reported 'easy' experiences of negotiating condom-use with her Nigerian boyfriend and other international AIDS activists that she had sexual relations with.

> because you must have a condom because of your HIV status. It is very important to disclose with your boyfriend. (Ntombi)

Others (such as Zoliswa) referred to the importance of disclosure in order to empower their lovers to assist with their health needs when necessary. They rarely emphasised the more romantic reasons for disclosure, such as wanting to disclose in order to 'protect the one they love', or cathartic reasons such as sharing their problems. Rather, the dominant discourse is one that recognises their instrumental needs and the fact that the man might find out anyway – in Buyiswa's case because of her activism, but also from signifying marks (e.g. scars from skin conditions caused by HIV) on their bodies, such as the HIV-related scaring experienced by Zoliswa, Thembi and Liziwe. Interestingly, Wong et al (2006) found that partners and spouses were the least likely to increase social support after disclosure, in addition to being the most likely to actually decrease social support (ibid: 219).

Some of the women, however, highlighted the potential emotional benefits of disclosing as a means of facilitating a more intimate relationship based on honesty and trust. For example, Thembi argued explicitly for disclosure as a positive act of intimacy rather than as an instrumental act. She believes that early disclosure is a risk worth taking because it will build trust and enable the honesty and sharing that is important for an emotionally meaningful sexual relationship. She said that her strategy had resulted in a lot of rejection from men (even though the men say they are leaving for unrelated reasons, Thembi does not believe them). Her subsequent insistence on using a condom has also not been without its challenges: she rejected a (married) American man who wanted to have unprotected sex with her despite knowing about her HIV status; and the man she was with at the time had problems maintaining an erection when using a condom.[65]

For Thembi, the very act of disclosure is a way of testing the worthiness of potential partner and giving him the opportunity to react within the context of an intimate relationship: if he leaves, he is clearly not who she would want to be with anyway; if he stays, she has contributed to building intimacy and trust.

[65] In Lene Leonardson's research on sexual behaviour amongst HAART patients in Kwazulu-Natal, she found that some men struggled to maintain an erection and satisfy their female partners when they wore condoms (Leonardson, 2007).

> It is important to disclose to your partner. Why not? Because in a relationship there are so many things that you share with your partner. So [many] beautiful things. I mean what is that person to you. Like you not giving the person the right to [say] how he feels. You don't know how he feels. You are just assuming that the person is going to react like that. (Thembi)

Others in the group (such as Lizeka, Liziwe and Zoliswa) agreed with her argument in principle, but in practice found it harder to live by. The rest, however, had such negative perceptions of men and cynical attitudes towards relationships, that disclosure in the interests of intimacy appeared almost incomprehensible.

The fact that Thembi and Liziwe were on HAART[66] (which means they have to take pills daily) and have scars from previous HIV-related skin conditions, no doubt encourages them to maintain this principled stance because explaining the pills and the marks without referring to HIV would entail telling lies – an action which in their eyes is even more morally dubious than simply choosing not to provide the relevant information. The analysis in Chapter 6 showed that the body often acts as a signifier of HIV infection, and the impact of physical signs and symptoms of HIV and HAART is exacerbated within sexual relationships, where covering up rashes, thrush or weight-loss is extremely difficult. The body is therefore a proxy for disclosure, and an obvious cause of stress for many of the women in sexual relationships in which they have not disclosed. However, if disclosure is an act of intimacy and pays off, it inevitably comes with other benefits. Zoliswa discusses the real potential for her to experience skin rashes and diarrhoea (both opportunistic infections of HIV) and her feeling that her man may need to provide her with support when she is ill.[67] These women's strong discourse in favour of building trust through early disclosure, and their recognition of their own psychological needs for intimacy, sets them apart from the rest of the group.

8.4 Disclosing in long-term relationships

Some women were (and remain) faced with the challenge of disclosing their HIV status to long-term established partners – i.e. men whose status as sexual partners preceded the HIV

[66] See Table 8.2 for details of which respondents are on HAART.
[67] At the time of the first interview in early 2004, Lizeka had not yet begun HAART but had begun to experience serious opportunistic infections including cancer in her eye and skin conditions. In mid-2005, she developed a serious cancer in her lymph glands in her neck and after months of chemotherapy started HAART.

diagnosis. Perceptions of the risks of disclosure in established relationships are similar to those reported for new relationships, i.e. rejection and possible boundary turbulence. However, in the case of established relationships, the risks are higher because of the emotional investment in that partnership, the potential for children to be involved, and the social context created around it. Furthermore, the woman faces the additional problem of potentially being blamed for bringing HIV into the relationship if condom-use had been inconsistent prior to the diagnosis. Such perceptions of risk must be contextualised in terms of whether or not condom-use has been consistent, the relative strength of the relationship, and the length of the relationship.

If condom-use was successfully negotiated at the start of the relationship (and condoms were used consistently subsequently), then the risk of HIV transmission is low, and hence the potential for blame (if the man finds out he is also HIV positive) are correspondingly low. But relationship risk extends beyond this: if the woman decides not to disclose immediately after learning her HIV status, then she runs an additional risk of earning his displeasure when she finally plucks up the courage to tell him because he may (understandably) be angry with her for withholding this important information from him. Thus, the woman may find herself in the stressful situation of wanting more time to build up trust in the man (and courage within herself) to tell him – but then may be rejected or censured for demonstrating that initial lack of trust and care for his well being. The risks of disclosure thus increase over time. Consistent condom use after diagnosis can help reduce this risk – but not entirely as a man may well feel that he would prefer not having a relationship with an HIV-positive person (even if condom use reduces the risk of transmission) and that it was her duty to tell him of her HIV status at the start. If she fears this reaction, then by not telling him, she tacitly accepts that she is having a dishonest relationship where it will never be possible to confide in him, or to empower him to assist her when she becomes sick.

The experience of the women in disclosing to established partners was varied, difficult to interpret and in some cases contradictory. Zoliswa, for example, disclosed to an established partner ten months after she learned she was HIV-positive. This relationship was sufficiently strong to endure this late disclosure, she says, however, the partnership subsequently terminated for reasons other than her HIV status. However, both Zameka and Sylvia were supposedly in loving relationships yet had not disclosed to their partners.

One of the most significant barriers to disclosure for the women was the fear that they would be blamed for bringing the virus into the relationship. This can lead to rejection, as Zameka explains her perceptions of men in general:

> [With] the other men: if his wife comes from the clinic and he comes from work; she says, "My husband, they said in the clinic I am HIV positive." The other men, they say, "No, you can take all your things and go because of this." (Zameka)

However, failing to disclose to the long-term partner has its own particular stresses. As Dunyiswa describes - he might find out from other sources and he may have been put at risk by mistake (e.g. if a condom broke, or in Dunyiswa's case where he found her HIV-related work papers under her bed). She is thus exposed to the charge that she brought HIV into the relationship.

> Because if you tell after we do the sex, everything, maybe the condom breaks. Then he is going to the clinic to test. He is positive. So he is going to blame you. [Or] maybe someone knows you are HIV positive then he will hear you are HIV positive, then he is going to blame you, maybe he is going to kill you. (Dunyiswa)

As discussed below, Dunyiswa did not disclose to her husband (who discovered her HIV status from reading her personal papers). Although she had not in fact transmitted HIV to him even though they were not using condoms (he tested HIV-negative), he left her anyway because she had 'brought' HIV into the relationship and put him at risk. It is clear that the longer they do not disclose, the greater the fear of an angry response to a future disclosure.

The women's fears of blame appeared to be linked to their struggles to convince their male partners (whether these were established relationships prior or subsequent to HIV diagnosis) to go for VCT and to use condoms. This reflects a broader social context in which men are under-represented in treatment programmes (Braitstein et al 2008; Bila and Egrot 2009) and are more likely to present late for testing and treatment, at more advanced stages of the disease and with greater risk of mortality compared to women (Keiser et al., 2008; Lawn & Wood, 2006). They may also be less likely to use condoms and seek HIV-related care than women (Beck 2004, Nattrass 2007) although a South African national survey found no significant differences between men and women seeking or knowing about VCT facilities (Shisana *et al*, 2005: 80). Research from other parts of Africa also suggests a general reluctance on the part of men to

address their possible HIV status. In their research on women presenting for ante-natal care in Nigeria, Farquhar et al found that despite the fact that 64% of women disclosed to their partners, only 15% of these partners reported for VCT (2004: 1626). Bila and Egrot (2009), in their research in Burkino Faso sum it up:

> "Representations of masculinity are fully implicated in the cultural construction of men's reluctance to attend care facilities for PLWH. The values associated with this masculinity cause men to run great health, economic and social risks, not only for themselves, but also for their wives and children." (2009: 854)

In terms of condom-use, many of the women in this study had successfully negotiated condom-use (in some cases threatening to leave the man if he refused, or actually leaving the man if he continued to refuse), yet in other cases they struggled even after their disclosure. Such findings highlight the conflicts and contradictions between their attitudes about men and condoms and their own experiences. Similarly, whilst mostly cynical about men and relationships, some of the women also reported experiencing love and support and hovering over the general condemnation of men is the hope that they will find a 'good' one. This is evident in the following section which describes actual experiences of disclosure and condom use.

8.5 Actual experiences of disclosure and condom-use in relationships

The overwhelmingly negative perception of men and relationships appears to have a strong influence on the decision to disclose. Nevertheless, many of the participants told of relationship experiences where men reacted supportively to their disclosure. With the exception of Sylvia and Zameka (discussed in more detail below), all the women had either disclosed to their sexual partners or, like Buyiswa, were in the process of disclosing. As discussed in Chapter 9, such high levels of disclosure amongst HIV-positive people on HAART in Khayelitsha are evident in the HAART survey.

8.5.1 New relationships, consistent condom-use and non-disclosure

Perry *et al.* (1994) point out that new relationships are more susceptible to failure as a consequence of one of the partners disclosing his or her HIV status, and as a result, those in new or fragile relationships may adopt the tactic of non-disclosure, or allowing the relationship to become stronger before embarking on full disclosure. This is a problem for public health if

failure to disclose is not accompanied by consistent condom use. The difficulty for policy-makers promoting disclosure as a means to encourage increased condom use is that people (especially women) may not trust their partner enough to disclose at the outset of a relationship and may even deliberately expose that partner to HIV if he is seen as refusing to protect himself (see Zameka's story below). Others, however, opt to keep their HIV status a secret if they do not trust their partner not to blame and reject them. However, as noted above, this dishonesty itself can expose the HIV-positive person to anger and blame at a subsequent stage (see also Dunyiswa's story below). But in a social and individual context where the HIV-positive person is unsure that a new relationship will last, then non-disclosure and condom use is the most rational strategy.

Buyiswa's account of her current relationship seems representative of a short-term relationship with consistent condom-use and non-disclosure. Even though she values the relationship, she is not sure it will last, and therefore feels that disclosure is not yet necessary. She says that she is using condoms consistently. In terms of the risks, she does not fear future blame (because she insists on condoms), yet she fears rejection. Both Buyiswa and Thembi claim to have had a number of partners in the recent past and disclosed to all of them. None of these relationships lasted and they attributed these break-ups to the fact that they may have disclosed too early in the relationship. Even though Thembi discloses to all potential men at the outset of relationships, she nevertheless understands and sympathises with Buyiswa's strategy with regards to disclosure and short-term relationships.

> Well in that case it's okay, because you are not serious about this relationship, you are just moving around and you are using a condom. How many people are you going to disclose to, if you like, one week you meet this guy, next week you meet [another] guy. …… I think it's okay for a relationship that long, but [not] a long relationship. (Thembi)

8.5.2 New relationships, consistent condom-use and disclosure

Some of the women recalled positive experiences of disclosure to sexual partners at the beginning of new relationships. As Lizeka (who favoured early disclosure as a way of ensuring condom use and building intimacy) recalled:

> When I had this boyfriend that I broke up with, I wasn't afraid to disclose to him because I just told myself that if he loves me then he will accept me in the way I am. And then that's what he did, accepted me the way that I am. So I am not afraid because I am HIV positive ... No, I will get someone and I will tell him if I am positive and then he will leave me or take me. (Lizeka)

Liziwe tells a similar narrative about getting back together with an ex-lover she had had a relationship with prior to her HIV diagnosis: She said that she disclosed as soon as that they got back together, as she did not want to wait for possible rejection further into the relationship when more was at stake.

> I said: "I am HIV positive. I am HIV positive and I am taking the treatment. Can I show you?" "Yes, you can show me?" And he said, "No, no problem. We are going to use the condom" I said okay but I think on last year August he left. I don't know where he is. (Liziwe).

However, as noted above, this relationship did not last and Liziwe was unclear why he left. Nevertheless, she, like Lizeka and Thembi, believed strongly that one should disclose and use condoms even in the face of possible rejection – or not have a relationship at all. Lizeka described her experience with a former boyfriend:

> My last boyfriend didn't want to use a condom … When I say, "hey my doctor said I must use a condom because I am on antiretrovirals", and I was explaining everything to him. And he was like saying, "Go to the doctor and tell him he must use a condom to his wife." Like something like that. It was hard but I forced him. I said, "if you love me and you don't want me to leave, then we must use a condom." It's very difficult for them to understand. I mean they don't want condoms at all, they don't want. Men, they don't want condoms. But you have to try and try and try. Because like HIV is caused by not using a condom. So I don't know what it is about them. (Lizeka)

Others referred to a time further into the relationships when the man will no longer want to use condoms. Disclosure therefore becomes part of a strategy to convince the man to use condoms at this later time. However, for some of the women, a key motivation for disclosure at the start of the relationship is in order that this situation does not arise.

> I think it is important to disclose to a boyfriend because what is happening, men are sometimes, when it comes to a condom, then they asking, "Why do you want us to use a condom." And then I think when you disclose to him, then it makes it easy for him to understand, why to use a condom. I think it's important. (Lizeka)

> I can say … some boyfriends say, "We can use a condom," but tomorrow he will say, "No, I don't want." So I decided to tell him that I am HIV positive so that he must know that this person is like that so we must use a condom for the rest of our lives. (Zoliswa)

In Zoliswa's case, this same boyfriend decided that he did not want to use condoms after they had been together for a while. She reported that he had been for two tests since her disclosure and tested negative both times. In this case, it was an HIV-negative man who wanted to practice unsafe sex with an HIV-positive women (i.e. expose himself to infection similar to Thembi's experience with the American man) – and it was the HIV-positive woman who wanted to use condoms not to protect him, but to protect herself from re-infection because she did not believe him when he said he was HIV negative! Zoliswa said she did not believe the tests – a view which she believes was vindicated by the fact that he tested HIV-positive at a later stage (after they had separated). This illustrates how negotiating condom use can be very tricky and can be an issue even after disclosure even if people know they are at risk – especially as relationships develop over time.

> He didn't want to use condom anymore. I told him that I am HIV positive and I am going to leave him because I don't want to be destroyed because I have children so I must think about my future. That's why I decided to leave him because I don't know whether his HIV is stronger than mine. (Zoliswa)

8.5.3 Long term relationships and inconsistent condom-use

If condom-use was not negotiated at the beginning of a relationship (or subsequent to HIV diagnosis in an established relationship) or if condom-use was inconsistent, the women may encounter both blame and rejection when their HIV status is disclosed. This is evident in Dunyiswa's account. As soon as she discovered that she was HIV-positive (she learned this from a routine pregnancy check-up), Dunyiswa told her boyfriend. He, however, reacted by saying that she must have been sleeping around and if he had the virus she would be to blame.

She therefore denied that she was HIV-positive and said she was joking and did not insist on condom use. Her major concern was being blamed for bringing HIV into the relationship rather than rejection per se. The consequence of her decision, however, was that she was unable subsequently to negotiate condom use with her boyfriend. When he later discovered she was HIV-positive (after reading some of her personal papers stored under her bed) he was very angry with her for not disclosing to him and because they had had unprotected sex. Even though her boyfriend tested negative, he still blamed her for potentially infecting him and left her.

> He found the papers and then read ... I was going to fetch some work or some water and when I came back he is reading the papers. I didn't take the papers, I was waiting until he finished. Then he said, "This is true?" I said, "Ja, this is true." Then he go to his family and then he talk about this. And then the family said that he must go test. So he go to the test then he came back, he said to me he tested negative. That the night [when] I was there he shouted at me, "It's you. You bring this virus. But god he saved me. But you, you want to give me this virus. You know for a long time you got AIDS." (Dunyiswa)

Zameka was also diagnosed while pregnant and had never disclosed to her husband of five years and did not insist on condom use. She said that she did not disclose to him because he refused to take responsibility for his own HIV status and go for a test. She justified her non-disclosure by arguing that her husband refused to go for a test when she asked him, so why should she risk being blamed for bringing HIV into the relationship when he does not even care about his own status? She therefore does not use condoms and assumes that he is also HIV-positive (but appears not to worry about re-infection). She argued that if she discloses prior to them being tested together, she will be blamed for bringing the virus into the relationship and requesting condoms would arouse suspicion. She believes that if she can convince them to be tested together, [68] a counsellor will be able to assist her in breaking the news to her husband that she is HIV-positive.

> Okay she said she wants to go together with him … Zameka can't go alone to say to him she is HIV positive. She will feel better when the counsellor can say, "Your wife is

[68] According to Semrau et al (2005), couple-counseled women in Lusaka, Zambia, were more likely to accept testing (96%) than women counseled alone (79%). However, six months after the testing, there were no differences in experiences of adverse relational events reported by the two groups.

> HIV positive, you [are] HIV negative." So he is going to get proper counselling at the clinic. That's why she wants to go with him, so that he can get counselling about her. (Zameka translated by Sylvia)

Her account of how she probably became infected indicates that she thinks she was infected by a sexual partner prior to her husband,[69] so if her husband turns out to be HIV positive, there is a high probability that she did indeed infect him. However, in the absence of Zameka's husband going for VCT together with her, it is highly unlikely that she will disclose and assume responsibility for possibly infecting him (if he tests HIV-positive). This resonates with the broader international literature. For example, UNAIDS reported that behaviour change within established relationships was unlikely unless both partners know their HIV-status (2004:15). Similarly, Farquhar et al (2004) found that in Nigeria couples counselled together in the antenatal setting were more likely to adopt prevention strategies such as avoiding breastfeeding and using condoms (2004: 1624). Zameka's attitude may therefore be well founded, as she has too much to lose.

8.5.4 Long-term relationships and consistent condom-use

Sylvia was diagnosed when she was pregnant, and at the time of interview, had not disclosed to her partner (and father of her child) of over three years who is in fact married to another woman. She was able to negotiate condoms after her diagnosis, and therefore does not fear being blamed for bringing HIV into the relationship, but rather fears rejection. The fact that she had been physically abused numerous times in her relationship did not feature explicitly in her perceptions of the consequences of disclosure. However, it is important to note the socio-economic dynamics of Sylvia's relationship. Even though she realises the possibility of rejection, she feels that because of her financial power over her partner (she in employed and he is not), he will not leave her.

> I don't think he can run away because he knows that if he runs away he won't get his child and he won't be with me. Because he is not working now, I am helping him. Like he is a smoking guy, so he wants to go out with his friends, I give money to go out with his friends and also to buy cigarette for him. (Sylvia)

[69] Zameka recalls how a previous boyfriend most probably infected her prior to her current marriage.

Zoliswa's account of her different relationships shed some light on the different issues involved in long-term relationships. Although she fears rejection, she argues that disclosure is a necessary ingredient of a loving relationship, even more so as it may ensure condom-use. She believes that to love a man means not exposing him to a potentially lethal infection, and that any man who genuinely loves her will accept her HIV status. In terms of specific relationships, she disclosed to her ex-boyfriend (the father of her second child) after 8-10 months. He reacted positively and went for a test. The test came back negative, and so did a second test some time later. She had been diagnosed while pregnant, and moved to consistent condom-use after her diagnosis. This point is a critical, as people often move from unprotected to protected sex after diagnosis (see e.g. UNAIDS 2004).

Since this boyfriend, she has had another, but she left him because he refused to wear condoms. This in itself suggested to her that he was not a man who loved her (she had, after all, seen him at the MSF clinic and suspected that he was HIV-positive and that he knew it). They started off their relationship using condoms, but then he demanded that they stopped using condoms, so she left him[70]. She was concerned about re-infection and felt that by taking personal risks; she was putting both herself and her children at risk.

Zoliswa's experience of her boyfriend's change of heart with regards to condom-use highlights a crucial time in a relationship where love, disclosure and condom-use collide. Such experiences are common with many of the other women, especially those with HIV-positive partners. Despite managing to negotiate condom-use at the beginning of a relationship, men may want to stop using condoms as the relationship strengthens and develops. It is at the stage when disclosure is necessary if it has not already occurred, as the very act of continuing to request condoms at this stage of the relationship tends to arouse suspicion.

> And in the relationship I always fear of your boyfriend not wanting to use condoms because of not knowing your status because you have a tendency of after three months being together just say, okay we know each other, I think we [are] healthy, let's not use a condom. And because that boyfriend don't know, you cannot say really no, I cannot we cannot not use the condom. Because they say why, you do not trust yourself, so don't touch me. (Buyiswa)

[70] This relationship was immediately prior to her marriage.

For this reason, some of the women argued strongly that it is better to disclose early on in the relationship, knowing that the relationship will inevitably come to this point. However, even though the women felt that the risks of disclosure were too high at the beginning of the relationship, they recognised that the risks were much greater later on (as Dunyiswa found out at the cost of her relationship).

8.6 Discussion

Hunter (2005) is correctly critical of interpretations of 'African sexuality' as being historically driven rather than shaped by changing social, cultural and economic contexts. Explanations of women's sexual behaviour and sexuality that remain similarly trapped within static historical or structuralist understandings of gender inequality are similarly unhelpful. There is an urgent need for research into women's changing views on, and experiences of, sexual relationships in contemporary South Africa, specifically those relationships experienced by HIV-positive women who have known their status for a number of years and thus may have experienced a number of different types of sexual relationships over time.

This chapter explored disclosure and condom-use amongst a group of HIV-positive women. The analysis identified key themes that emerged from the qualitative data. These themes included: the negative perceptions of women towards men as a result of current relationships and those prior to their diagnosis; whether women believe that a good relationship is possible (and hence use disclosure as a 'test'); the importance of relationship duration in affecting costs and benefits of disclosure; and the ways in which women made choices that affected how honest and open they were going to be with their partners. The findings showed that the relationship between disclosure and condom-use is neither consistent nor simple and in many cases conflicting. Despite such conflicts and difficulties, the respondents were by no means passive or submissive recipients of the injunctions of men, and were well aware of their vulnerability within relationships and the specific risks posed by their HIV status.

The study has several limitations. Firstly the sample is not representative of all HIV-positive women in Khayelitsha as many had been involved in AIDS advocacy work and all were employed. However, many of the accounts described by the women resonate with my numerous discussions with women in support groups in clinics in different townships around Cape Town. The study may be biased in terms of women's perceptions of men, and was not

counter-balanced by men's perceptions and accounts of relationships. As Hegeman et al (2009) note with regard to their research on sexual and reproductive behaviours amongst 779 couples in Rwanda, "Rwandan husbands and wives differed in sexual behaviour and reproductive-related topics. Couple-level reporting provides the most reliable measure for relationship aspects as couples' agreement cannot be assumed among cohabiting partnerships" (2009:47). Nevertheless, considering that the findings in this research show that women have considerable decision-making power that may put their own and their partner's health at risk, it is critical that we understand HIV-positive women's perceptions, motivations and fears with regard to relationships.

Even though the study participants believed that disclosure would probably lead to rejection and possibly blame, many of the women reported positive responses when they decided to disclose. These included condom use, intimacy and support. And, although some did experience rejection because of HIV, they also reported relationships ending for non-HIV related reasons. Some women also opted to reject the men for not wanting to use condoms, which is could be framed as both an HIV and non-HIV related reason.

The participants are not new to issues around disclosure or negotiating condom-use considering average duration since diagnosis was approximately four years with an average of two sexual relationships per participant since diagnosis. Over time, they had developed capacities and strategies for dealing with men's injunctions and the risks posed by disclosure. In a longitudinal qualitative study of African American women in New York, Buseh and Stevens found that their respondents were able to negotiate the constraints of stigma, disclosure and condom-use better as time since diagnosis increased (2006:15). As Poindexter (2005) points out with regards to Ervin Goffman's (1963) seminal work on the management of a stigmatized identity:

> "When the condition is hidden or not obvious, as in the case of HIV, then fear of discovery or disclosure may become even more pronounced. Lessening the effects of stigma can go beyond the management strategies discussed by Goffman. A stigmatized person or someone with associative stigma may reject or actively resist the pejorative labelling." (Poindexter 2005: 65).

As such, PLWH are not only receiving end of a disempowering context, but actively confront it in order to defend themselves and their loved ones (ibid.). Many of the women in this study had

a principled stance towards disclosure, in which they disclosed at the beginning of relationships and demanded condom-use. They were willing to risk rejection, yet were also willing to reject the man if he refused to wear condoms. For others unwilling to risk the consequences of disclosure, they actively concealed their HIV-status from their long-term partners in order to maintain maximum control over their position within their relationships - even if this meant potentially harming the men.

While many of the accounts of disclosure in this study were positive (due to careful reflection on the part of the women about the men they were deciding to disclose to), the women nevertheless felt anxious about future disclosures. Such an apparent contradiction between perceptions/fears and experiences of disclosure may be related to the perceptions of stigma in the broader community as revealed in the qualitative data discussed in Chapters 5 and 6. PLWH are burdened by the perception that stigma and discrimination are rife in their communities (Thomas *et al.*, 2005; Swendeman *et al.*, 2006). The narratives of sexual relationships described in this Chapter show a similar tension.

CPM theory may also shed some light on the persistent negative perceptions of disclosure, as the decision to disclose conflicts with the desire for independence and privacy. According to Greene et al (2003), the decision to disclose is based on the discloser's willingness to include the disclosure recipient in his/her privacy boundaries (see Chapters 3, 5 and 6). HIV positive people want to control the flow of information about their HIV status – which is why the decision about who to disclose to is important and difficult. It entails allowing the person being disclosed to into their 'privacy boundary' where confidences are respected (Petronio 2002). But HIV disclosure always carries the possibility of boundary turbulence. This is especially a problem in a social context where men are not particularly trusted and fear of gender violence is common, but where there are clear advantages to disclosing to the men who are, or about to become, sexual partners.

In addition to wanting to maintain control over their 'HIV secret', these women also want control over their sexual lives – even more so as time progresses, and they learn to negotiate the challenges that come with being a Xhosa woman living with HIV. The persistent perception that men (especially Xhosa men) cannot be trusted, that negotiating condom-use is difficult and disclosure usually leads to rejection, has a substantial impact on the women's ability to live a life independent of their HIV status. So while CPM aims to provide a framework for understanding the dialectic between privacy and disclosure, the narratives of sexual

relationships of this group of women require that CPM is extended to include managing the dialectic between power and vulnerability – between sexual agency and a social context that constrains and oppresses them.

The women's perception of men's careless (and sometimes fatalistic) attitude towards condom-use was confirmed more often than not. Difficulties in convincing men to use condoms were experienced at the beginning of relationships in addition to further into the relationship where the relationship had strengthened to a degree where the men felt that condom-use was no longer necessary. In general, negotiating condom-use at the beginning of new relationships appeared to be less problematic than in established relationships. However, in some cases, men also chose not to use condoms even after disclosure (and were rejected by the women for this stance).

Refusing to use condoms, even after the women have disclosed their HIV status, perhaps indicates a level of fatalism on the part of men. Campbell's (2003) research on the mines in South Africa, and Seeley and Allison's (2005) research on fishing in the Great Lakes region showed similar fatalistic attitudes towards condom-use and risky sexual behaviour. US-based studies with both MSM and women have also cautioned against assuming disclosure will automatically lead to condom-use because of the important influence of broader socio-cultural factors driving sexual behaviour (Serovich and Mosach 2003; Crepaz and Marks 2001). However, notwithstanding the fact that men's attitudes towards condom-use are socially constructed, it is important not to see these as fixed and immutable. As evidenced from the above narratives, men are open to persuasion and their attitudes to condoms are often relationship-specific.

US-based studies on condom-use amongst young adults with STDs (Katz et al 2000) and with HIV-positive women (Simoni et al 2000) have shown that condom-use changes as the dynamics of relationships change. In a meta-analysis of the psychosocial determinants of condom-use in 121 studies of heterosexual relationships, Seeran et al (1999) showed that there was a strong and consistent association between condom-use and relationship-type. Condom-use is generally more frequent and more easily negotiated in casual and 'newer' relationships because partners are unfamiliar with each other's sexual histories. As the relationship develops, couples or individual partners may choose to forego condom-use as an act of intimacy and trust. In the case where a partner is diagnosed during marriage such as the case with Zameka, levels of intimacy may already exist and negotiating condoms may arouse suspicions of

infidelity (Worth 1989). As such, diagnosis during established relationships is a more stressful and potentially more traumatic experience because condom-use is more difficult to negotiate and disclosure embodies higher risks. In Zameka's case, she responded by not disclosing and not using condoms, thereby exposing her husband to HIV. In Dunyiswa's case, she failed to disclose, and when her husband found out by other means that she was HIV positive, he left her for being dishonest and exposing him to HIV. Managing relationship risk is thus problematic whether the women opt to disclose, or not to disclose.

Difficulties with negotiating condom-use and in getting men to go for VCT, may also reflect a wider socio-cultural phenomenon of constructions of masculinity that result in lowers levels of health-seeking behaviour adopted by men (see Nattrass 2008c; Beck 2004; Campbell 2003). The 2006 wave of the KSPS survey provides some interesting indications of the differences between men's and women's perceptions of men's health, which also ties in to differing gendered perceptions of relationships. For example, 89% of female respondents and 69% of male respondents agreed or strongly agreed with the statement "Men think of ill-health as a sign of weakness which is why they go to a doctor less often than women" (p=0.000).

The women's experiences of negotiating condom-use and their perceptions of men's attitudes towards VCT also point to a key issue in the gendered nature of current prevention strategies, specifically male condoms. According to the accounts of the women, only once did a man initiate condom-use (and only after her disclosure). The responsibility of public health thus appears to be primarily in the hands of women (- see also Campbell 1995: 209). As Simoni et al argue "Many interventions advocating male condoms operate as if the women themselves were donning them rather then having to persuade their male partners to within the context of a relationship that may be precarious if not perilous." (2000: 692). Women are thus supporting the goals of public health, yet they may also be risking their individual well-being by challenging culturally prescribed roles in which women may not demand certain behaviour from men (Travers and Bennet 1996; Susser and Stein 2000). Furthermore, Susser and Stein (2000:1048) point out that it may be culturally inappropriate for a woman to request a change in a man's behaviour thereby challenging his authority, while she is able to control her own body with minimal interference from men. Therefore, public health interests may benefit from female initiated forms of protection such as the female condom and other new technologies (Tolan 2005). However, analysis presented in this chapter also shows that woman can and do challenge cultural preconceptions around condom use (and indeed use disclosure as a tool to encourage or force condom-use), so an unduly pessimistic stance is inappropriate.

Chapter 9: Quantitative analysis of HIV disclosure amongst PLWH on HAART in Khayelitsha

This chapter revisits the survey data of PLWH on HAART in Khayelitsha described in Chapter 4 and analysed in Chapter 5. The following quantitative analysis of disclosure experiences using the survey data allows us to investigate the extent to which the themes arising from the disclosure narratives discussed in Chapters 6, 7 and 8 are evident amongst the wider population of PLWH. A key finding in the previous chapters was that disclosure experiences are dynamic and are influenced by the social, physical and psychological aspects of living with HIV. A number of broad areas emerged that were of particular importance to people's experience of the disclosure, especially as they disclosed to significant others within the household. These included: stage of disease when diagnosis and disclosure took place; whether respondents had begun HAART; how individuals managed to psychologically cope with living with HIV; their needs for care and support; and their desire to educate others. In the case of disclosure to sexual partners, both the motivations above and more were evident. These include: duration of the specific relationship; whether they knew their status prior to the relationship or were diagnosed during the relationship; knowledge of their partner's status; their overall trust in men; and the ability to negotiate condom use. This chapter explores these concepts within the KSPS 2004/5 and 2006 samples – a significant proportion of the first people to be part of the public sector HAART rollout in South Africa.

Where Chapter 5 used the survey data to explore the stigmatising context and experience of stigma in Khayelitsha amongst PLWH on HAART, this chapter focuses on actual disclosure experiences, rates and correlates as reported by the survey respondents. The analysis also explores correlates and determinants of the complexities of disclosure within sexual relationships. And, following from the qualitative analysis of public disclosure in Chapter 6, this chapter also uses the survey data to explore the determinants of public disclosure.

9.1 Measures

Individual Background

Gender, age, education and socio-economic status were measured in the survey. As discussed in previous chapters, both gender and age are important covariates in understanding disclosure

experiences. The analysis in Chapter 8 showed that women find it more difficult to disclose in sexual relationships because they do not want to be blamed for bringing HIV into the relationship, they often have little trust in men, and do not want to risk possible violence. The level of education is potentially important as more educated respondents might be able to form better disclosure strategies and thus avoid potential negative consequences of disclosure to sexual partners. For socio-economic status, the analysis uses two variables to capture income. Firstly, the analysis includes a dummy variable which takes the value of one if the respondent reported either being in wage employment or self-employed. Secondly, the analysis uses receipt of a government disability grant as a proxy for whether the person has access to some income even if they are not employed. Including some kind of income measure in the analysis is helpful, as for women that are economically dependent on men, the risk of rejection and abandonment may therefore result in them choosing not to disclose (Makin et al 2008). Conversely, and as was evident in Sylvia's narrative, she thought that her boyfriend would not abandon her as she was the breadwinner in the relationship.

Measures of HIV disclosure

The survey asked respondents in the second wave of the study (2006) for details on disclosure in four ways (see Appendix D for disclosure module from KSPS 2006). Firstly, respondents were asked a general question on how many people were aware of their HIV-positive status. The response to this question was used to get a sense of the respondents' general openness with their status in addition to the question being used as a proxy for 'public' disclosure. The public disclosure variable was defined as a dummy variable taking a value of one if the respondent reported that more than 50 people were aware of their HIV-positive status. The assumption made here is that as it is practically impossible to manage a privacy boundary with 50 people, this amounts, in effect, to a broader 'public' disclosure.

Secondly, the survey assessed whether respondents had disclosed to specific audiences (e.g. to fathers, mothers, cousins, brothers, church, etc.), when in the disease trajectory these disclosures occurred (before or after starting HAART), and the response of the specific audience to their disclosure (a qualitative response). Information on disclosure experiences in a wider range of contexts is important because it shows the diversity of the person's disclosure network, which on one hand indicates available options for social support, but on the other hand, allows us to control for experiences of stigma amongst those respondents who had disclosed widely and therefore increased the possibility of experiencing negative events.

Thirdly, respondents were asked to describe up to four specific disclosure experiences in detail in order to get more granular data on individual disclosure experiences. Because of a poor response rate for the fourth experience, the analysis uses data from the first three reported experiences (see Appendix D). Lastly, the survey asked respondents about their sexual relationships in the 12 months preceding the survey, and assessed whether or not the respondent had disclosed to their sexual partner, condom-use behaviour, when they disclosed to this partner, the reaction to their disclosure, and in the case of those who had not disclosed, why they chose not to.

Disease progression and self-perceived health status

As described in Chapter 3, Alonzo and Reynolds (1995) conceptualise PLWH's experience of stigma as part of a 'stigma trajectory' where PLWH experience different levels and types of stigma based on their health status which is a function of the changing manifestations of HIV-disease over time. Similarly, the qualitative analysis in Chapters 6 and 7 showed that a key reason for disclosure was to either receive support as a result of the severity of their illness or that they had little choice as the symptoms of HIV (or scars) were impossible to hide, especially from intimate partners. The analysis here therefore includes two measures to determine the potential influence of health status on disclosure. Firstly, the survey asked whether respondents had experienced skin problems as a result of their treatment in the past three months (as this is a side-effect that is very difficult to hide especially in sexual relationships). Secondly, the analysis also calculated treatment duration as the number months between starting HAART and the month of the interview. It was hypothesised that physical signs and treatment duration would adequately capture health status. Further, a variable was created to measure the length of time respondents had known their HIV status by calculating the number of months between when the respondent reported being diagnosed and the time of the interview.

Relationship characteristics

The qualitative analysis in Chapter 8 showed that the nature of the sexual relationship in which the disclosure decision is made is very important. For example, in casual sexual relationships where condom use may be easier to negotiate, a number of the participants did not feel the need to disclose. However, in long-term relationships, disclosure was critical both in terms of

respecting and nurturing trust in the relationships as well as minimising risk to partners (albeit difficult to negotiate). Studies that have looked at the type of relationship in which disclosure takes place (see e.g. Akani and Erhabor (2006) in Nigeria and Loubiere et al (2009) in Cameroon) found that married respondents were more likely to disclose than unmarried respondents. However, as Hunter points out (2006), marriage rates in South Africa are declining and are very low amongst Blacks. The survey therefore asked whether the sexual partner was either married/spouse or somebody they loved but were not married to. The survey measured a proxy for the duration of the relationship by calculating the time between when the respondent reported first having sex to the time of the interview.

Whether the respondent lives with their sexual partners is an important covariate and is likely to have an impact on disclosure especially at advanced stages of HIV disease. Both the physical manifestations of HIV and the need for active management of the disease (e.g. six monthly CD4 counts and monthly visits to the clinic to pick up ARVs) is likely to force the HIV-positive person to disclose as hiding visible signs may not be possible when living in such close proximity with another person (especially in a shack or small house typical of Khayelitsha). The qualitative analysis in Chapter 8 showed that trust in men and male partners is an important factor in the disclosure decision making process. The analysis therefore includes further variables which may proxy for the level of trust in the relationships such as whether the partner has met family and friends.

The final variable to measure the nature of the specific relationship is a measure of concurrency. The variable takes a value of one if either the respondent reported that they think their partner definitely had other sexual partners or if the respondent themselves definitely had other sexual partners during their relationship.

HIV-testing and knowledge of partner's status

Knowledge of partner's status or even knowledge of whether the sexual partner had been for an HIV test may also have an impact on the decision to disclose (Gari et al 2010; Makin et al 2008). Denison et al (2007) showed that access to VCT was correlated with a reduction in sexual risk behaviours. If the HIV-positive person's partner has had an HIV test, this may signal that a sympathetic hearing of their disclosure narrative is more likely. Further, if VCT included counselling on safer sex, the partner may also be more likely to practice safer sex. The

analysis includes a variable on whether the respondent knew that their partner had been for an HIV test.

Social Capital

The extent to which people trust others was a salient factor in the decision making process for the respondents in the qualitative study. Those with very little trust in their own community, and those had experienced gossip in their neighbourhood, experienced more difficulties in deciding when and where to disclose, or at least with further disclosures in more public settings. A social capital index was thus created (by creating an average score of the responses to questions in Table 8.4) to determine people's general levels of trust in society – as evidenced by their trust in different groups of people (Alpha = 0.81)

Table 9.1: Individual items used to build social capital index

How many people in each of these categories can be trusted, in your opinion?
Nurses and Doctors
Politicians
Your colleagues at work (if you work)
People from your racial group
People from other racial groups
Teachers
Policemen/women
People from your religious group
People from other religious groups
Members of your family
People who work in government offices, e.g. at the Department of Home Affairs

9.2 Results

To explore the correlates and determinants of disclosure in general, in public and to sexual partners, univariate analysis, bivariate analysis and multivariate logistic regressions were used. For normally distributed continuous variables, two sample t-tests were used, while for categorical variables either χ^2 or Fisher's Exact tests were used depending on the size on the category sample size (i.e. Fisher's Exact tests were used where sample size is less than ten).

9.3 General rates of disclosure: Who are people disclosing to?

Rates of disclosure in the sample were high with 100% of respondents reporting disclosing to at least one person. Over 90% of the sample reported disclosing to spouses/partners, 81% disclosed to family members in the household, 79% to parents, 73% to relatives outside the household, and 79% disclosed to friends. The data suggests that rates of disclosure decrease as the proximity of the relationship declines. 'Proximity' in this case is defined as either biological relations residing within or outside the household. Only 54% of the total sample had disclosed to neighbours, 49% to co-workers (those that were wage/self-employed), 43% in the church and lastly 35% to the community.

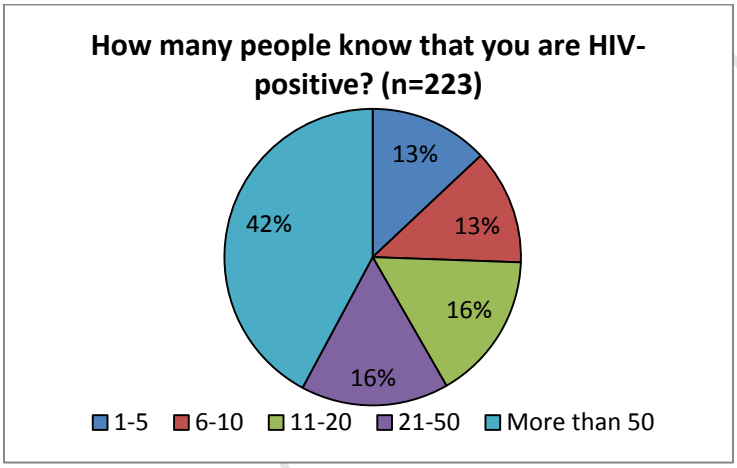
There were some important gender differences. All (100%) men in the 2006 survey reported disclosing to their sexual partners compared to 88% of women (p=0.016) following on from a similar relationship between gender and disclosure in the 2004/5 survey. The survey also asked respondents to agree or disagree with following statement in order to measure general experiences of stigma and levels of support received by PLWH: "When HIV made me very sick my close family members were willing to take care of me". Over 95% of respondents either agreed or strongly agreed with the statement, indicating a favourable environment for disclosure in the household context.

Table 9.2: Disclosure rates by relationship type

Categories of relationships	Disclosed	
Spouse/ partner	%	91%
	n/N	181/200
Parent	%	79%
	n/N	143/181
Family member (in household)	%	81%
	n/N	173/215
Relative (not in household)	%	73%
	n/N	158/217
Friend	%	79%
	n/N	173/220
Neighbour	%	54%
	n/N	120/222
Colleague/Co-worker	%	49%
	n/N	48/98
Church	%	44%
	n/N	69/157
Community/Public disclosure	%	35%
	n/N	72/207

The survey also asked respondents for an approximate number of people that know that they are HIV-positive[71] (see Figure 9.1). Interestingly, 42% of the sample reported that over 50 people are aware that they are HIV-positive, while only 13% reported that between one and five people know their status. While the difference was not statistically significant, it is useful to point out that 44% of women had disclosed to more than 50 people compared to 33% of men (p=0.199). This may also be indicative of the fact that more women than men are TAC members in Khayelitsha and women are more likely than men to be members of support groups.

Figure 9.1: Numbers of people aware of respondents HIV status



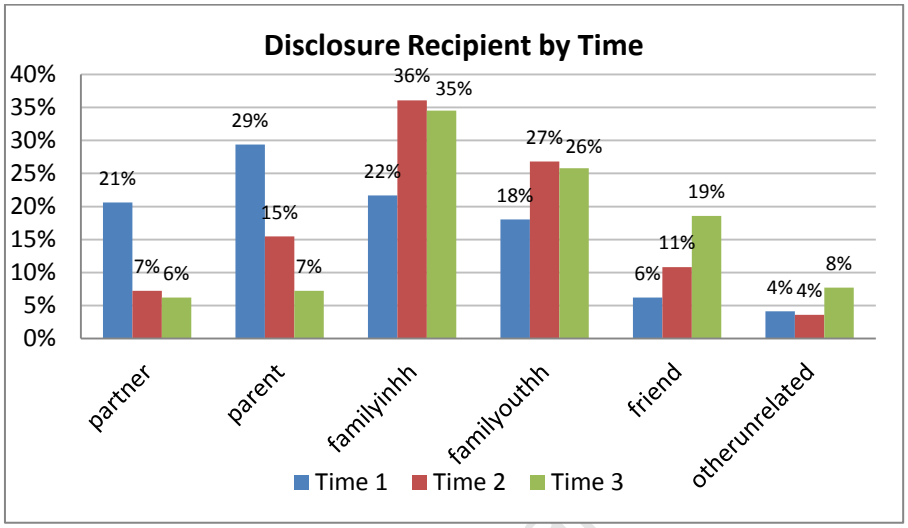
Order of disclosure experiences

The data on specific disclosure experiences suggests a similar picture to that which may be drawn from the general rates of disclosure shown in Table 9.2. Patterns of disclosure appear to be determined by proximity and the obvious and trusting relationships in which people usually access support. Respondents were asked to describe in detail their first four disclosure experiences[72]. (Throughout this chapter, these first four disclosure experiences are referred to as Time 1, Time 2, Time 3 and Time 4). The data suggests that PLWH disclose to close significant others first, with 86% of respondents disclosing to partners, parents, family in the household or family outside the household[73]. The proportion of respondents disclosing to

[71] Due to the wording of the question we do not know if they actually disclosed to people or if they found out from other sources. However, the survey asked whether the respondent personally disclosed to specific relationships categories as in table 7.3. The highest number of involuntary disclosures was reported in the neighbour category with 11 of 120 respondents reporting that they did not personally disclose.
[72] Data is drawn from the first three disclosure descriptions due to poor response rate for the fourth.
[73] We do not know how many people had sexual partners at the time of diagnosis, or at the time of disclosure. Thus, was choosing to disclose to a sexual partner even a possibility? However, even if we ignore disclosure to partners, the trend remains the same.

family outside the household, to friends and to others increases in the second and third disclosure. For example, only 6% of respondents reported that their first disclosure was to a friend, increasing to 11% and 19% in their second and third disclosures respectively (see figure 9.2).

Figure 9.2: Disclosure recipient choice by time



Does gender of the disclosure target matter?

The data reported in table 9.3 suggests that women are statistically more likely to disclose to women while men are more likely to disclose to women but this is not significant. In the three specific disclosure experiences asked about, men disclosed more often to women, and to an even larger extent, women disclosed more often to women.

Table 9.3: Gender of respondent, gender of disclosure target (excl. partners), and disclosure experiences

	Men			Women		
	Male target	Female target	Total	Male target	Female target	Total
Time 1	36% (9)	64% (16)	100% (25)	14% (18)	86% (111)	100% (129)
	P = 0.195			P = 0.027		
Time 2	48% (15)	52% (16)	100% (31)	21% (31)	79% (118)	100% (149)
	P = 0.730			P = 0.144		
Time 3	32% (10)	68% (21)	100% (31)	23% (34)	78% (117)	100% (151)
	P = 1.000			P = 0.005		

Note: Numbers in parentheses indicate the number of respondents; percentages do not always total 100% due to rounding effects

Time since diagnosis and disclosure

Table 9.4 explores the relationships between the length of time somebody has been HIV-positive and disclosure to specific targets. There is no statistical relationship between time since diagnosis and disclosure to significant others, specifically spouses/partners, parents, family members in the household and family members outside the household. The analysis does however show that there is a significant relationship between the length of time somebody has known their status to disclosure to friends, neighbours, in the workplace, at church and in the community. For example, respondents who report disclosing to neighbours, also report knowing their status for 16 months longer than those who have not disclosed to neighbours.

Table 9.4: T-test of the relationships between time since diagnosis and disclosure to specific audiences

	Spouse/ partner	Parent	Family member in HH*	Relative not in HH	Friend	Neighbour	Workplace	Church	Community
Did not disclose									
Mean	60	63	68	61	56	78	54	58	58
SD	36	17	34	26	21	20	20	21	23
Disclosed									
Mean	66	66	63	67	67	94	70	76	71
SD	27	31	26	28	29	31	24	33	28
Mean difference between disclosers and non-disclosers									
Difference	-6	-3	5	-6	-11	-16	-16	-14	-17
T-statistic	-0.78	-0.47	0.9	-1.18	-2.08	-4.06	-3.18	-3.00	-4.17
P-value	0.4336	0.639	0.3452	0.2383	0.0388	0.0001	0.0022	0.0032	0.0000

*Household; SD = standard deviation

Table 9.5 also looks at the relationship between the disclosure target and when the disclosure occurred in relation to initiating HAART. The majority of respondents disclosed within closer household relationships prior to commencing HAART. Disclosure in significant relationships before HAART (parents, family in the household, family outside the household and friends) ranges between 70% for family outside the household to 85% for parents. Disclosure to partners is inconsistent with other relationships, and we do not know which partner the respondent is referring to. Disclosure to neighbours, in the workplace, in the church and in the community before HAART ranges from 45% for disclosure in the church to 56% for disclosure in the workplace.

The survey also asked respondents to rate their health status at the time of their first four individual disclosure experiences (see Table 9.6). On a scale from 1 – 10, with 10 representing

the healthiest, median self-reported health status increases from 3 at Time 1 to 6 at Time 4. The data suggests that earlier disclosures were correlated with lower self-perceived health status. However, we need to be careful about making the causal link between health status and disclosure, as all of the respondents are on HAART and therefore have experienced their health improve over time.

Table 9.5: Choice of disclosure targets in relation to initiating HAART

Timing	Spouse	Parent	family in household	family outside household	Friend	neighbour	workplace	church	community
N	180	143	173	158	143	120	48	69	72
# Disclosed	112	121	138	111	112	63	27	31	37
Before	62%	85%	80%	70%	78%	53%	56%	45%	51%
After	38%	15%	20%	30%	42%	48%	42%	54%	47%

Note: Percentages do not always total 100% due to rounding effects

Table 9.6: Self reported heath status at the time of individual disclosure experiences

	Time 1	Time 2	Time 3	Time 4
Mean	4.1	4.5	5.1	5.8
Median	3	4	5	6

9.4 Disclosure to sexual partners

In 2004/5, 87% of the sample had disclosed to their current sexual partner, with a higher proportion of men (94%) than women (85%) disclosing to their sexual partners – although this was not a statistically significant difference (p=0.112). In 2006, all men reported disclosure while only a slightly higher proportion of women disclosed compared to the 2004 survey. It is important to note that attrition analysis in Chapter 4 indicated that the sample did not lose a significant proportion of non-disclosers between waves.

Table 9.7: Disclosure to sexual partner by gender in KSPS 2004/5 and 2006

	2004/5		2006	
	Have you disclosed to your sexual partner		Have you disclosed to your sexual partner	
	Yes	No	Yes	No
Men	93% (43)	7% (3)	100% (39)	0% (0)
Women	85% (128)	15% (22)	88% (121)	12% (19)
Total	87% (171)	13% (25)	89% (160)	11% (19)
	P = 0.112		P = 0.007	

Note: Numbers in parentheses indicate the number of respondents; percentages do not always total 100% due to rounding effects

Table 9.8 shows a bivariate and multivariate analysis of important potential correlates of disclosure to sexual partners amongst women in the survey using a logistic regression. It was not possible to do a statistical analysis for men as 100% of the male respondents reported disclosing to their sexual partners in the 2006 survey.

In the bivariate analysis, disclosure to sexual partners was not related to any of the demographic and socio-economic variables. Certain relationship specific variables did however show a statistical relationship with disclosure to sexual partners amongst the women surveyed. Women who reported that their partners knew other members of their family were almost four times more likely to have disclosed (p=0.048). Secondly, those women who report living with their partner were almost five times more likely to disclose (p=0.014). Thirdly, women who reported that they knew their partner had gone for an HIV test for were 20 times more likely to disclose, indicating that a relationship in which HIV is openly discussed is highly conducive to disclosure. It is important to point out that the wide confidence interval and the stretch of the relationship could be due to a small number of observations for this variable. Interestingly, the survey data did not show a relationship between the length of the sexual relationship and whether disclosure had occurred. This is consistent with the qualitative study which illustrated how complex the decision to disclose can be, how contingent it is on relationship dynamics and why there is no necessary reason to expect length of relationship to be neatly correlated with likelihood of disclosure.

Table 9.8 also includes a multivariate analysis of disclosure to sexual partners for the females in the sample (n=140). The multivariate model was used to determine whether the variables shown to be statistically significant in the bivariate analysis remain significant when controlling for other variables that would like have an influence on disclosure decision making (giving us the adjusted odds ratio). Interestingly, the same three variables (knowing family, cohabiting, and whether the respondent knew that their partner reported having an HIV test) remained statistically significant.

Table 9.8: A bivariate and multivariate analysis of HIV disclosure to sexual partners in the past year amongst women participants (n = 140) - All males reported disclosure to sexual partners in 2006

	Disclosed to sexual partner		Bivariate Analysis		Multivariate Analysis	
	No	Yes	Odds Ratio	95% CI†	Adjusted Odds Ratio	95% CI†
Relationship Status						
spouse/married	1	17	1.00		1.00	
someone you loved but were not married to	16	98	0.36	0.05 - 2.89	6.81	0.28 – 168.39
someone you knew well but did not love	2	6	0.18	0.01 – 2.32	0.3	0.01 – 8.05
Employment Status						
wage or self employed	7	56	1.48	0.54 - 4.01	1.43	0.33 – 6.13
Disability Grant Recipient	11	52	1.04	0.39 - 2.76	1.57	0.39 – 6.28
Education						
Greater than 7 years education	16	104	1.15	0.30 - 4.36		
Friends and Family						
know members of family	15	113	**3.77***	1.01 - 14.04	**5.92***	0.75 – 46.93
know friends	17	114	2.24	0.42 - 11.99		
Co-habitation						
Live in same house as partner	3	68	**4.98***	1.38 - 18.02	**8.22***	1.06 – 63.08
Infidelity						
partner have other sexual partner	8	48	0.92	0.34 - 2.45		
respondent have other sexual partners	5	24	0.70	0.23 - 2.13		
Concurrency	9	62	0.55	0.19 – 1.57	1.02	0.28 – 4.10
HIV test						
partner had an HIV test	2	85	**20.07*****	4.41 - 91.4	**53.15*****	7.16 – 394.54
Condom use						
Consistent condom use in past year	11	66	0.89	0.33 - 2.37	1.00	0.28 – 3.45
Time on HAART	38.1	39.5	t = -0.4427		1.02	0.97 – 1.07
Relationship duration	60.1	68.8	t = -0.5627		0.99	0.98 – 1.00
Physical signs of illness	9	68	0.89	0.34 – 2.36	1.18	0.31 – 4.44
					Observations	170
					LR chi2(12)	45.58
					Prob > chi2	0.000
					Pseudo R2	0.38
					Log likelihood	-36.79

* p<0.1; ** p<0.01; *** p <0.001
† CI – 95% confidence interval

Reasons for non-disclosure to sexual partners

The KSPS 2004/5 survey asked respondents about reasons for non-disclosure to sexual partners in previous relationships. The reason for non-disclosure given highest importance by the sample was that respondents thought that the person being disclosed to would not believe them. The second most common reason for non-disclosure was a concern that the partner would get angry and hurt them. In general there is no statistical relationship between this variable and gender, however it is important to note that 10% more men than women rated this particular concern (anger and violence) as not important.

Table 9.9: Reasons for non-disclosure of HIV-status to sexual partners

Think of sexual partners you have **not** disclosed to. How important were the following reasons?	Not important	Slightly important	Important	Very Important	Very, very important	Total
1. You thought they would reject you	41% (76)	23% (42)	15% (29)	15% (29)	5% (9)	99%
2. You thought they would stop providing financial Support	45% (81)	24% (45)	16% (30)	12% (22)	3% (6)	100%
3. You did not trust them not to tell other people	49% (90)	25% (47)	14% (26)	9% (17)	3% (5)	100%
4. You thought they would not believe you	35% (64)	13% (24)	38% (69)	13% (24)	2% (3)	101%
5. You thought they might get angry and hurt you	40% (73)	17% (31)	22% (42)	10% (19)	10% (19)	99%
6. They were not important enough in your life	47% (87)	26% (48)	22% (40)	4% (8)	1% (1)	100%

Note: Numbers in parentheses indicate the number of respondents; Percentages do not always total 100% due to rounding effects

In the 2006 survey, 19 women reported not having disclosed to their current sexual partner or to their most recent sexual partner within the past year. As is shown in Table 9.10 the most widely reported reason for non-disclosure was fear of rejection: "I was afraid my partner would leave me". Two respondents reported that their partners did not like the condom as a reason for non-disclosure, and another two respondents reported they were afraid their partner might get angry. Fears of losing economic benefits, fears of boundary turbulence, treatment optimism, or experiences of stigma did not have a significant impact on the decision not to disclose. Interestingly, fear of rejection was least important when asked about non-disclosure in general, while it was the most important reason respondents reported when asked about a specific relationship. This may be as a result of a methodological issue with the way the question was asked or the specific relationships the respondent was thinking about at the time.

Table 9.10: Reasons for non-disclosure to sexual partners amongst female respondents in 2006 (n=22). All males reported disclosure to sexual partners.

Why have you not disclosed to your partner?	n
I was afraid my partner would leave me	13
My partner did not like the condom	2
I was economically dependent on my partner	1
I was afraid my partner would tell other people	2
I was afraid my partner would get angry	1
My partner had negative attitudes towards PLWHA	2
I was using condoms so I thought he/she was protected	1

Disclosure and Condom-Use

A key reason for disclosure in sexual relationships is to facilitate a reduction in risky sex behaviour and condom-use in particular (Simbayi et al 2007). This reason was highlighted in the qualitative analysis in Chapter 8 where a number of the women disclosed specifically to encourage their partners to use condoms. Almost all the women in the qualitative analysis reported that they often experienced problems convincing men to use condoms in the context of both relationships in which they had or had not disclosed.

Table 9.11 presents data from questions posed to survey respondents in KSPS 2006 regarding their primary relationships. The data does not suggest any strong relationship between disclosure and the dynamics of both condom use and the negotiation of condom use in the sexual relationship described. The data does however show that women are disadvantaged when it comes to condom use negotiation, with 29% of women reporting that they do not use condoms every time with their current sexual partner compared to 10% of men (P=0.012). A significantly higher proportion of women (26%) also reported that they had arguments about using condoms compared to men (8%; P = 0.007). Even though the sample size is too small to make broad conclusions, it is interesting to point out that the dominant reason reported for not using a condom amongst disclosers was that condoms reduce pleasure, while for non-disclosers the two reported reasons were that the partners would be suspicious of their status if they asked to use a condom or they did not know how to discuss condoms.

Table 9.11: Condom-use negotiation by gender and disclosure in the primary sexual relationship

	Gender (N=182)		Have you disclosed to this sexual partner? (N=179)	
	Male	Female	No	Yes
	40	142	19	160
When you had sex with [partner], how often if ever did you use a condom?				
N	39	140	19	158
Every time	90%	71%	74%	76%
Not every time	10%	29%	26%	24%
	P = 0.012*		P = 0.510	
Why don't/didn't you use condoms with this partner?				
N	6	35	5	36
S/he is positive	33%	9 %	0 %	14%
Condoms reduce pleasure	50%	37%	0 %	44 %
Condoms would make my partner suspicious of my positive status	-	20%	60 %	11 %
Found it difficult to discuss	-	17%	40 %	11 %
Did not have condoms with me	17%	6%	0 %	8 %
Wanted to have a child	0%	11%	0 %	11 %
	P = 0.475		P = 0.025*	
Who generally made the decision not to use a condom?				
N	4	39	5	37
Myself	50%	10%	20 %	14%
My partner	25%	41%	60 %	38%
Joint decision	25%	49%	20.%	49%
	P = 0.179		P = 0.428	
Have you ever disagreed or had arguments about using condoms with this partner?				
N	40	140	19	159
Yes	8%	26%	32%	21%
No	92%	74%	68%	79%
	P = 0.007**		P = 0.231	

* p<0.05; ** p<0.01; *** p <0.001
Note: Percentages do not always total 100% due to rounding effects

9.5 Determinants of public disclosure

The following section uses the survey data to get a better understanding of the correlates and determinants of public disclosure. As was shown in Chapter 6, public disclosure is accompanied by a number of risks to the person disclosing. It was clear from the narratives of the group of women, that public disclosure was more suited to the more activist members of the group (even though all of the group disclosed publically in some way), and not all of the women felt comfortable disclosing to audiences or settings where they felt that knowledge of their HIV-status could get to people within their own community or neighbourhood. Thus, this section uses the survey data to further our understanding of the characteristics of PLWH who

are more likely to disclose publically, thereby enabling future interventions that rely on public disclosure to be more targeted in their recruitment of participants.

As discussed in Chapter 6, the decision to disclose publicly is determined by weighing up both the self-interested and other-interested risks. This decision making process aims to minimise the potential negative consequences of public disclosure (while maximising personal benefits), by carefully selecting audiences for disclosure information. The decision to disclose to specific audiences was mediated by proximity to the individual, type of media used, individual activist ideologies, subjective constructions of community, group and professional pressures, and most importantly, perceptions and fear of the potential negative consequences as a result of being identified as HIV-positive by both people they know and do not know.

A number of variables were included in the analysis as potential factors that would likely influence the decision to disclose publicly. Whether the respondent tries to keep their HIV status a secret is an obvious determinant of whether they would choose to disclose publicly. However, the qualitative analysis suggested that public disclosure is still common even when some of the research participants had not disclosed in their private lives, demonstrating that for some of the participants, they (correctly or incorrectly) perceived there to be clear boundaries between their private and activist lives.

Considering that the survey location was Khayelitsha, it is likely that a number of respondents were members of TAC or other activist organisations. Being a member of TAC would likely be a strong determinant of public disclosure. However, the questionnaire did not ask about TAC membership specifically. Thus, the analysis includes employment and member of a community group as potential proxies for either being a member of TAC or being employed by an NGO such as the Memory Box Project or *mothers2mothers*.

A further potential determinant of public disclosure is support group membership. Being a member of a support group for PLWH would obviously increase the numbers of people disclosed to. However, being a member of a support group may also encourage the individual to engage in more activist behaviour as they are encouraged to be open with their HIV-status.

An important consideration when disclosing publicly is whether or not people have already disclosed in the private context to members of their households or their sexual partners. As discussed in Chapter 6, a number of the women determined where they would disclose

publicly, by weighing up the likelihood of whether their 'secret' could be found out by people their community. Disclosure to sexual partners was included in the analysis as it is likely that those who had not disclosed to their sexual partners had the most to fear from having a wider circle of people 'in the know' because this is likely to increase the risk of that partner hearing about the respondent's HIV status from others.

Lastly, the Social Capital index is included in the analysis as whether a person chooses to disclose publicly is likely influenced by their general trust in society in both managing their secret and in a positive response. Table 9.12 shows the results of the individual items that make up the index, which as described above were summed to for the overall index. Family members and nurse and doctors are clearly the most trusted groups.

Table 9.12: Average scores for individual items making up social capital index

How many people in each of these categories can be trusted, in your opinion?	Mean	Median	SD*
Nurses and Doctors	4.6	5	0.8
Politicians	2.9	3	1.4
Your colleagues at work (if you work)	4.1	4	1.1
People from your racial group	3.8	4	1.1
People from other racial groups	3.4	4	1.2
Teachers	4.3	5	1.1
Policemen/women	3.7	4	1.3
People from your religious group	4.4	5	0.9
People from other religious groups	3.7	4	1.1
Members of your family	4.6	5	0.7
People who work in government offices, e.g. at the Department of Home Affairs	3.7	4	1.2
Total	34.6	35	6.14

* SD = standard deviation

Public disclosure analysis and regression results

Table 9.13 shows the bivariate and exploratory multivariate regression analysis of the determinants of public disclosure. To calculate the odds ratio in the bivariate analysis, I conducted a bivariate logistic regression with 'public disclosure' as the dependant variable against each of the independent variables listed in the table. In the multivariate analysis, the adjusted odds ratio was calculated using the same 'public disclosure' variable as the dependant variable, with all the independent variables listed in the table included in the regression.

As expected, whether the respondent chooses to keep their HIV status a secret is a strong determinant of whether they have disclosed publicly. Whereas the clinic they receive HAART

from (a rough proxy of neighbourhood) was significant in the bivariate analysis, with the base being Site B, it was no longer significant in the multivariate analysis. Compared to the base for the clinic variable (Site B), receiving ones HAART from the 'other' clinic was both significant in the bivariate and multivariate analyses. Similarly, respondents who report receiving HAART from the 'other' clinic are also less likely to want to keep their HIV status a secret. These results points to the importance of the clinic where one receives HAART or ones neighbourhood as a significant predictor of public disclosure. However, only 10 respondents report receiving their HAART so the impact of this particular variable must be interpreted with caution.

As expected, treatment duration is significant in both bivariate and multivariate analyses. For every additional month on HAART respondents were 4% more likely to report disclosing to more than fifty people. The only other statistically significant predictor of public disclosure was whether the respondent was a member of a support group. Respondents who reported being a member of a support group were more than four times more likely to have disclosed publically, and almost five times more likely when controlling for other factors. This could be interpreted in two ways. Firstly, because of the changing membership of support groups in Khayelitsha – where there are often twenty PLWH attending – it is likely that more than fifty people know the respondents HIV status simply by virtue of belonging to a support group. However, the results may also reflect the fact that membership of a support group gives people the confidence to disclose to people outside of the group as well.

Table 9.13: Bivariate and multivariate analysis of public disclosure

Determinants of Public Disclosure N=223 (total sample); n=94 (those who report disclosing to more than 50 people)	Bivariate Analysis		Multivariate Analysis	
	Odds Ratio	CE	Adjusted Odds Ratio	CE
Female	1.58	0.78-3.21	2.09	0.83-5.27
Clinic				
Site B	1.00			
Michael M	2.37*	0.98-5.69	1.66	0.5-5.49
Nolungile/Site C	2.79***	1.52-5.12	1.59	0.67-3.76
Other	5.96**	1.43-24.76	11.21**	1.54-81.89
Wage or self employed	1.35	0.77-2.3	0.80	0.36-1.75
Disability Grant Recipient	0.75	0.44-1.28	0.86	0.40-1.86
Do you try keep HIV a secret	0.12***		0.16***	0.06-0.42
Disclosure to sexual partner	2.56*	0.88-7.46	3.12	0.79-12.31
Time on HAART	1.04***	1.02-1.07	1.04**	1.01-1.07
Social Capital Scale	0.95*	0.91-0.99	0.96	0.90-1.02
Belong to support group	4.54***	1.71-12.04	4.99**	1.24-20.15
Belong to community group	1.25	0.83-2.39	1.30	0.59-2.84
* significance at 10%;		Observations		171
** significance at 5%;		LR chi2(12)		60.33
*** significance at 1%;		Prob > chi2		0.000
		Pseudo R2		0.2559
		Log likelihood		-87.7

9.6 Discussion

The results from the survey analysis show extremely high rates of disclosure amongst this sample of PLWH on HAART in Khayelitsha. One hundred percent of respondents had disclosed to at least one person with a significant proportion reporting that over fifty people are aware of their HIV status. Even though studies on disclosure in Africa do show relatively high rates of disclosure, no studies have shown such high disclosure rates. This is almost certainly a consequence of Khayelitsha's status as being the first public sector HAART rollout in South Africa and the related activism (including the *LongLife* project discussed in Chapter 6) around it. It may also be a reflection of the fact that the survey respondents are some of the longest surviving patients on HAART in South Africa (and Africa more broadly) and rates of disclosure often increase over time as PLWH increasingly come to terms with their diagnosis, especially as their health improves over time due to HAART (and all respondents are on HAART).

A pattern of disclosure to significant others emerged, reflecting similar findings to Chapter 7. PLWH disclose most frequently to close household members (e.g. partners, parents, family members in the household), while waiting some time to disclose within less significant relationships or in public settings e.g. to members of the church. In addition, female household members such as mothers and sisters were selected as primary disclosure targets in both the qualitative and quantitative analyses – which in almost all cases resulted in expected positive support. The importance of family members in this study as the primary resource for PLWH to access support following their diagnosis is comparable to other studies in South Africa (e.g. Varga et al 2005; Nachega et al 2005; Skogmar et al 2006) and Africa more broadly (Miller and Rubin 2007). The fact that disclosure to close family members occurs soon after diagnosis is supported by the analyses of the relationship between the length respondents had known their HIV status and disclosure and the time of disclosure in relation to initiating HAART. Disclosure to parents and family members within the household almost always occurs before initiating HAART. Similarly, the analysis of individual disclosure experiences and the choice of disclosure target is also related to health status. As the proximity of the person or group they disclosed to increased (i.e. first to mothers and sisters, and later to neighbours and the community), so did their self-perceived health status. And considering that the progression of HIV disease does not change rapidly, initial disclosures likely occur when PLWH are sick, and disclosure in relationships or in settings outside the household occur when PLWH perceive their health to be improved. While Alonso and Reynolds (1995) argue that experiences of stigma change in relation to the physical manifestations of HIV disease, the data presented in this chapter also seem to suggest that disclosure choices and targets change over time in relation to improving health status and starting HAART.

It was hypothesised that the specific dynamics of sexual relationships would have a much greater impact on disclosure decision making than was actually found in the quantitative analysis. Knowledge of whether one's partner had an HIV test had the strongest relationship with disclosure to sexual partners amongst women in the sample. Given the cross-sectional nature of these questions (these questions were not asked in the 2004 survey), we do not know the direction of causality – whether disclosure led to their partners having an HIV test or if knowing that their partners had an HIV test meant it was easier to disclose. We also do not know whether they knew their partners HIV status before the relationship began. However, reactions to disclosure to sexual partners were by and large positive, with only a small number of women reporting a negative experience.

A primary reason for advocating disclosure within sexual relationships is in order to increase safer sexual behaviour through the consistent use of condoms (Medley et al 2004; Serovich 2001). The results however did not show a relationship between condom use behaviour and disclosure. Of the 41 respondents who reported using a condom inconsistently in the year prior to the survey, it is interesting to note that of the five who had not disclosed, three reported that condoms would make their partner suspicious of their HIV status and two found it difficult to discuss. In a limited way, this indicates that some of the concerns expressed in the qualitative interviews discussed in Chapter 8 are somewhat evident amongst other PLWH in Khayelitsha. The survey may however not be adequately capturing the disclosure experiences amongst the sample because the median relationship duration was 52 months. Thus, if the survey asked only those who had not disclosed about their reasons for not doing so, it does not capture the experiences of the majority of the sample who at some point in time (and likely a number of years prior to the survey) were going through the process of deciding whether or not to disclose to their sexual partners and how to do this. The survey should also have asked respondents to think back to the time where they were making the decision and the reasons and barriers for disclosing or not disclosing at that time, or ask more details around the timing of disclosure within specific sexual relationships. Unfortunately, these questions were not asked and the data cannot shed light on these issues.

Even though it is difficult to make conclusions about the impact of gender on disclosure decision-making and sexual relationships due to the small sample size of men in the survey, there is a difference between men and women when it comes to disclosure to sexual partners, and sexual relationships more broadly. All men reported disclosing while 12% of women reported not disclosing. Actually, the data suggests that gender might be more of a salient factor in sexual relationships than disclosure. Women are less likely to report using condoms consistently, men are more likely to make the decision to use a condom, and women are more likely to report having arguments over condom use. Additionally, a significantly higher proportion of men reported having sex in the past year. This may also indicate that sexual relationships are relatively easier for men than they are for women. As indicated by Chapter 8, a number of the women expressed a desire to remain single, not only to avoid the disclosure decision, but also to avoid the consistent difficulties they faced in relationships with men.

The analysis used a range of measures to test the relative strength of the specific sexual relationships. This included the duration of the sexual relationship, whether the partner had met family or friends, if they lived with the partner, and whether there was concurrency. Amongst

the female respondents, knowing friends and family and whether they lived in the same household as their partner were the only variables with statistically significant relationships to disclosure. In terms of co-habiting with their partner, and as discussed previously, it is obvious that the physical manifestations as well as the active management of HIV disease either forces or necessitates disclosure. Meeting friends and family however may be a result of increased trust in the male partner and in the relationship more broadly which could therefore lead to disclosure. Interestingly, the analysis did not find a link between potential concurrency and disclosure – with concurrency being the ultimate measure of the strength of a relationship.

Despite asking whether their partner had been for an HIV test, the survey did not ask whether the respondent knew the results of the test and whether the partner was HIV-positive or negative. This should have been asked as it would have added critical information about the nature of relationships where either both partners were HIV-positive (concordant) or where only the respondent was HIV-positive (discordant). In the *LongLife* book, which includes the narratives of the same women interviewed as part of this thesis, Bongiwe stated that she wanted a husband who was HIV-positive so 'he could understand' the issues she had to deal with and could avoid the difficult disclosure and condom use discussions (Morgan and the BWG 2003:100). It is important to note however that obtaining information on partner's HIV status is difficult due to both ethical issues (we would be asking the respondent to disclose their partners HIV status) and due to the fact that many women do not know the HIV status of their partners as they have either not been for a test or have not told them as described in Chapter 8.

The fears of disclosure amongst the women who had not disclosed were consistent with the findings from the qualitative analysis, where fears of rejection and violence from partners usually dominate other concerns. This reflects the social context. As Matthews et al (1999) found in their study of HIV-positive women in Cape Town, 13% experienced violence and 9% were abandoned by their partners. Similarly, Sigxaxhe and Matthews (2000) found that fear of rejection was a dominant reason for non-disclosure amongst their sample. Maman et al (2004) found in Tanzania that the key driver for non-disclosure was fear of partner's reaction (including abandonment and loss of financial support). This study found that fear of rejection dominated, followed by fear that the partner would get angry and lastly, that the partner did not like to use a condom. The third fear is problematic as it assumes that disclosure is aimed exclusively at ensuring condom use. It is interesting that some respondents did indeed agree with this assumption and therefore listed this barrier as their dominant barrier to disclosure.

Even though fears of disclosure to sexual partners are widespread, it is important to point out that negative reactions to disclosure were infrequent, in terms of disclosures to sexual partners and in other relationship contexts. In the case of disclosure to sexual partners, only 3% of men and 7% of women reported that their partners became 'more horrible' after disclosure. We do not know what their partners were like prior to the disclosure so this findings needs to be interpreted with caution, especially as violence in relationships in South Africa is widespread (Jewkes et al 2009). It is important to point out that this finding should not belittle the gravity of the experiences of the few who have had negative experiences when disclosing to their sexual partners, especially as the reaction could be extremely violent as indicated by the story of Mpho Motluang who was murdered by her husband after he found out her HIV status. However, it is significant that so many of the respondents reported that partners reacted positively. This finding dove-tails with the qualitative analysis in which the fear of negative reactions to disclosure did not always materialise in the actual experiences of the women in which disclosure was usually met by positive reactions and responses.

The findings on public disclosure are important in that they may indicate something specific to the sample. Khayelitsha is often considered as the nexus of the struggle for access to HAART and PMTCT in South Africa (see e.g. Nattrass 2007; Hodes and Holm-Naimak 2012). This may be reflected in the significant proportion of the sample who reported that more than 50 people were aware of their status, and two-thirds of respondents reported that they had disclosed their HIV status to everyone in the household by the time they started HAART. Only three respondents reported that a (single) household member had been unsupportive. Both bivariate and multivariate analyses showed that those respondents who were members of support groups have the highest likelihood of significant numbers of people being aware of their HIV status. This finding is expected and points to the importance of this variable in the analysis. One might have argued that disclosure to large numbers of people would be largely as a result of support group membership. However, the data suggests that PLWH who report that more than 50 people are aware of their HIV status are also more likely to reporting disclosing to neighbours, at work, at church or in the community with increasing likelihoods respectively. Considering that support groups are usually located within or near the clinic, such high levels of disclosure in these public settings indicates that the high levels of public disclosure are not being driven by support group membership alone. We are unable to say that being resident in Khayelitsha is the primary factor driving such high levels of public disclosure because this was not measured specifically and we have no comparison to PLWH in other geographical areas. However, because of such high levels of support from community-based organisations and

NGOs, and greater access to HIV-related services through both the Western Cape Government and civil society, Khayelitsha may be a more sympathetic location for PLWH. The extremely high rates of disclosure to household members and to sexual partners found in the survey may also be attributed to Khayelitsha as the location of the study.

Chapter 10: Conclusion

One of the most important and stressful decisions for people living with HIV (which remains a highly stigmatised disease) is why, when and to whom to disclose their HIV status. Disclosure is the act that locates the HIV-positive individual at the nexus between the private (both psychological and physiological) and the public (social and cultural) spheres. Yet disclosure is also important because the impact of non-disclosure is significant, and includes poor care-seeking behaviours, a lower likelihood of preventative behaviour, stress and mental health problems, amongst others. However, disclosure has importance beyond the individual and is therefore not only an act impacting on the individual and those in close relationships with them. Disclosure in public settings and to the general population is an important tool in addressing stigmatising perceptions of others in the general community (TAC 2010).

Many studies have looked at disclosure using theoretical frameworks from the field of psychology, thereby encouraging an individualistic approach to understanding the dynamics of disclosure. While mental health is an important aspect of the disclosure experience (especially as disclosure was reported as an extremely cathartic experience), this research found that practical reasons such as seeking support or educating others dominate other reasons for disclosure. Further, disclosure is most often contextualised in terms of AIDS-stigma: namely that lack of disclosure is attributed to fear of stigma, and the experience of disclosure linked to the experience of stigma. AIDS-stigma is a significant aspect of the experience of living with HIV, but problemetising living with HIV exclusively in terms of stigma biases the analysis towards identifying the negative experience and places too much emphasis on the HIV-positive status of the person rather than seeing them as individuals whose life choices are shaped by changing social context which includes stigma, but as importantly, also includes the important dynamics of poverty and gender.

In addition, this thesis has shown that the various social and contextual effects related to HIV are dynamic and do not function in uniform way for all people. Rather, in both the qualitative and quantitative aspects of this study, it was evident that multiple experiences over time within individual biographies were simultaneously at play in producing and shaping their experiences of living with HIV and their disclosure strategies. Such biographical factors produced variation in strategies of disclosure, and reactions towards the discloser within and across multiple relationships in the household, to sexual partners and in public.

In order to explore these rich and diverse factors, the theoretical framework used in this thesis drew on multiple data sources, techniques and disciplines. In particular, four frameworks were used: the risk society approach; Communication Privacy Management Theory; the 'stigma trajectory'; and general stigma theory. The combination of these approaches supported a broad understanding of the experience of disclosure and living with HIV more broadly, using CPM to understand individual strategies of balancing the benefits and risks of disclosure, risk society and stigma theory to understand the social context in which people make their disclosure decisions and the consequent responses, and the stigma trajectory to frame these theories within the context of the changing nature and manifestations of HIV disease itself.

The research used a multi-method approach including in-depth interviews, participant observation, and a structured longitudinal survey amongst the first cohort of HAART patients in the public sector in South Africa. This is the first study to employ such a comprehensive methodological approach to disclosure in South Africa. In terms of the findings, no other study to my knowledge has found such high levels of disclosure amongst PLWH. In the quantitative data, collected from 242 PLWH on HAART in Khayelitsha in 2004/5 and followed up again 2006, 100% of respondents disclosed to at least one person and 42% reported that more than 50 people are aware of their HIV status. The analysis also shows that disclosure to sexual partners occurred in amongst 100% of men in relationships in 2006 (increasing from 94% in 2004/5) and 88% of relationships reported by women in 2006 increasing from 85% in 2004/5.

The qualitative data provide rich accounts of the many disclosure experiences of a group of HIV-positive women in Khayelitsha who formed part of the initial HAART pilot project. These women, many of whom were TAC members, found themselves having to balance their activist and personal lives – a situation commonly experienced by those choosing to disclose publicly. This study shows how they struggled to balance the need to disclose publicly to achieve advocacy goals with the risks and benefits of disclosure to family, friends, sexual partners and neighbours. The narratives suggest that disclosure should not be conceptualised as a single act because the dynamics of public and private disclosures are very different (as are the dynamics of disclosure in familial and intimate contexts) and happen over time as PLWH engage in multiple disclosures to various audiences in their lives. In the public space, disclosure is mediated by choice of audiences, social distance, type of media, activist ideologies, subjective constructions of community, and importantly, perceptions and fear of the risks resulting from being identified as HIV-positive. In all cases, the women developed carefully constructed

strategies for minimising risks and maximising the potential benefits to them, either in gaining much needed support when they are sick, addressing negative perceptions of HIV amongst friends and family, or to use their HIV status as a way to earn income.

At the household level, the relationships between the individual and other household members are characterised by both high and low levels of risk. Family members are usually and likely the most trusted people in people's lives. They are also critical and reliable providers of social support, specifically related to dealing with the manifestations of HIV disease itself in addition to important emotional support. However, because of such reliable support, and even though there may be significant amounts of trust, the risk of a negative response to disclosure is significant. In other circumstances, high levels of risk are usually related to low levels of trust. Despite the obvious risks, both the narratives from the women and the quantitative data showed that the support received from close family members (mothers in particular) was fundamental in enabling the participants to cope with the illness psychologically and physically, specifically prior to accessing HAART. The narratives also indicated the stress they felt when deciding to whom they would disclose, particularly in the household, even though it seemed quite obvious to them of those household members who would likely provide support and a give a positive response. The quantitative data also showed very high levels of social support received from household members, with very few instances of negative responses or reactions. The high levels of support are possibly due to both long-established familial bonds and also the careful process undertaken to select the most appropriate household member to disclose to.

The research found that disclosure within sexual relationships is highly complex with additional and more profound risks and benefits to the individual, especially when it is women who are disclosing. The data suggests that the decision making process is hugely stressful for the person disclosing, in part because they may be blamed for bringing HIV into the relationship simply because they know their positive status, and because of longstanding mistrust in men. It is also stressful in so far as the discloser may be seeking some form of support or attempting to educate or change their partner's behaviour. In addition to wanting to maintain control over their 'HIV secret', these women also want control over their sexual lives – even more so as time progresses and they become a healthy person living with a chronic but manageable illness. The persistent perception that men cannot be trusted, that negotiating condom-use is difficult and disclosure usuallycal leads to rejection, has a substantial impact on the women's ability to lives independent of their HIV status. The narratives of sexual relationships of this group of women require that the disclosure dialectic is not just between

privacy and disclosure, but needs to be extended to include managing the dialectic between power and vulnerability – and between sexual agency and a social context that constrains and oppresses women. Thus, the gendered nature of the society is which these women live both exacerbates the challenges of living with HIV and is often the primary driver of decision making. This last point underlies an important gap in this research. While it is fundamental that women are at the centre of the response to the AIDS epidemic, our understanding of masculinity and HIV from the male perspective is lacking. It could be argued that because of the disproportionate impact of HIV on women, and the consequent focus on women in research and by interventions, that men have been marginalised. Future research should address this form of gender imbalance.

While the quantitative data cannot conclusively show that experiences of stigma have decreased over time, there are some strong indications that this might be the case. This is an important finding, as while Maughan-Brown (2009) found that stigmatising attitudes actually increased over time in Cape Town during the same time period (despite the HAART rollout), this data suggests that these attitudes may not always be translated into corresponding stigmatising behaviours. However, despite this probable decrease, experiences of stigma continue to be reported in the 2006 survey with a few respondents even reporting increased stigma. The most common and significant form of stigmatising behaviour experienced by the qualitative and quantitative respondents in Khayelitsha is being gossiped about within their neighbourhood and community. Thus, the social costs of being gossiped about and publicly devalued remain a major problem for PLWH, and a challenge which needs to be overcome when negotiating who and when to disclose their HIV status to.

This study also highlighted the importance of both the multi-method and multi-disciplinary approach to looking at complex behaviours such as disclosure within the context of both a stigmatised disease and a changing social context. Quantitative data is important for more generalisable findings and broader conclusions in addition to gauging the experiences of a much larger sample, but it is often unable to capture the nuances of the experience of living with HIV, especially as experiences are determined by the changing nature of HIV disease and multiple and changing inter-personal relationship dynamics over time with both family members, friends and sexual partners. By using the multi-method approach to explore the experience of living with HIV through the lens of disclosure, the research has identified the ways in which PLWH are not just powerless victims, but play an active role in shaping the

various spaces in which they and others live, including making the decision to put themselves or others at risk.

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Appendix A: HAART Survey Consent Form

Centre for Social Science Research, University of Cape Town
Private Bag, Rondebosch 7701http://www.uct.ac.za/depts/cssr

CONSENT FORM

Last year you generously agreed to be a part of this panel study. A panel study is one in which we re-interview people regularly. This panel study explores the lives of people using anti-retroviral treatment. It is run by researchers at the University of Cape Town. We would like to re-interview you now.

You are kindly invited to participate in the 2006 survey. Before you decide whether to take part, we want to make sure that you understand the following information about the study.

What is the purpose of the study?

The University of Cape Town is doing research to assess the experiences of people using anti-retrovirals. The questionnaire again asks about work, living arrangements, health and sexual relationships. It is our expectation that the results from this study will improve our understanding of the health and work experience of many South Africans today.

What are the possible benefits of participating?

There will be no direct benefit to you; however the information we obtain from this study will give policy makers a better understanding of the lives of people living with HIV who are taking antiretrovirals. What you have to say could play an important role in improving the lives of people living with HIV, those who need antiretroviral treatment and those who are currently taking treatment- including yourselves.

What are the possible drawbacks or discomforts in participating?

This is only a survey; however, the issue of HIV/AIDS is very personal and sensitive. Some people may find it painful to recall and discuss their own experience.

Do I have to participate?

Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage and this will in no way affect your ARV treatment.

What will happen to me if I participate?

Information regarding your experience with anti-retrovirals will be recorded and treated confidentially.

Will the information be treated confidentially?

Yes, should you agree to participate in the study, all information collected for this study will be kept strictly confidential. Individual responses to our questions will never be made public, and no information which could identify you or your household will ever be released.

Contact details

If you have questions about this interview contact Thembi Hlwele (Tel 021-650-5117 fax 021-650-4657 or Email: nhlwele@commerce.uct.ac.za).
This study has been reviewed and approved by the Centre for Social Science Research Ethics Committee.

I, ... (name of respondent in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study. I have received a copy of this consent form.

Signature of respondent	Date

Interviewer/fieldworker: I have:

Explained the nature and purpose of the study to the respondent	N	Y
Handed over a copy of the consent form	N	Y

Signature of interviewer/fieldworker	Date

Appendix B: Examples of Qualitative Interview Schedules

Thembi

1. What is your feeling about disclosure? What is the meaning of disclosure for you?
2. Could you talk to me about your personal experiences with disclosure?
3. Do you feel that it is important to disclose to boyfriends or sexual partners?
4. In the focus group Buyiswa said that if you are using a condom with a partner then you don't have to disclose – what do you think about this?
5. What has it been like with Xolani, he already knew your status? Did this make it easier
6. I know you have disclosed to your family, can you tell me how?
7. Can you tell me how things have been in your family since you disclosed?
8. Do you talk to your family about HIV? How much do they know about HIV?
9. Are there any people that you have not disclosed to that you would still like to disclose to?
10. In the focus group many of you spoke about how important disclosure is. However some people only disclose to a few people close to them and some disclose openly even in the community. Do you think that it is important to disclose to the community?
11. Do you ever fell pressure to disclose to more people?
12. Does it make a difference disclosing when you have a job and are earning money?

Lizeka

1. What is your feeling about disclosure? What is the meaning of disclosure for you?
2. Could you talk to me about your personal experiences with disclosure?
3. Do you feel that it is important to disclose to boyfriends or sexual partners?
4. In the focus group Buyiswa said that if you are using a condom with a partner then you don't have to disclose – what do you think about this?
5. Do you have a boyfriend? Have you disclosed to him. Tell me about how it happened
6. You have one child, is that right? Have you disclosed to him/her?
7. Who else have you disclosed to?
8. In the focus group many of you spoke about how important disclosure is. However some people only disclose to a few people close to them and some disclose openly even in the community. Do you think that it is important to disclose to the community?
9. Do you ever feel pressure to disclose to more people?
10. Does it make a difference disclosing when you have a job and are earning money?

Appendix C: Relevant Questions on Disclosure from KSPS 2006

Section E: DISCLOSURE
(Questions E1.1 – E5 taken from CHSRD 2005)

Do the following people know about your HIV status? If YES ➔ If NOT APPLICABLE ⇩ If NO ⇩					↴ If YES: Did you personally tell them that you are HIV positive?			Was this before or after commencing the ARV Treatment Programme			What happened after this person found out your HIV status?	
Category		**NA**	**No**	**Yes**		**No**	**Yes**		**Before**	**After**		
E1.1	Spouse/ partner	9	2	1	E2.1	2	1	E3.1	1	2	E4.1	
E1.2	Parent	9	2	1	E2.2	2	1	E3.2	1	2	E4.2	
E1.3	Family member (in household	9	2	1	E2.3	2	1	E3.3	1	2	E4.3	
E1.4	Relative (not in household	9	2	1	E2.4	2	1	E3.4	1	2	E4.4	
E1.5	Friend	9	2	1	E2.5	2	1	E3.5	1	2	E4.5	
E1.6	Neighbour	9	2	1	E2.6	2	1	E3.6	1	2	E4.6	
E1.7	At work place (colleague / co-worker)	9	2	1	E2.7	2	1	E3.7	1	2	E4.7	
E1.8	Church	9	2	1	E2.8	2	1	E3.8	1	2	E4.8	
E1.9	Community (public disclosure)	9	2	1	E2.9	2	1	E3.9	1	2	E4.9	

E1.10	**Interviewer Readout:** We would now like to get an idea approximately how many people in total know that you are HIV-positive. **Interviewer read options.**	Number of People	
		0	1
		1-5	2
		6-10	3
		11-20	4
		21-50	5
		More than 50	6

E5 CHSRD05	Do you currently try to keep your HIV status a secret?	YES	1	
		NO	2	E7

E6 All from **CHSRD05**	**Do any of the following make it difficult for you to keep your HIV status a secret?**	Please Circle		E6.2 Circle which option makes it **most** difficult **(circle only one)**
		YES	NO	
E6.1.1	It is difficult to take my ARV medication without others noticing	1	2	1
E6.1.2	Storing the ARV medicines	1	2	2
E6.1.3	It is difficult to conceal the physical signs of my illness, e.g. loss of weight	1	2	3
E6.1.4	It is difficult to explain bouts of illness, i.e. being hospitalised, bedridden, or the ambulance arriving at my house	1	2	4
E6.1.5	People gossiping	1	2	5
E6.1.6	Going to the clinic	1	2	6
E6.1.7	Other (specify)	1	2	7

E7*	Think of the people you have not disclosed to. How important were the following reasons? **(Show card)**	Not important	Slightly important	Important	Very important	Extremely important
E7.1	You thought they would tell other people without your permission	1	2	3	4	5
E7.2	You felt too ashamed to tell them	1	2	3	4	5
E7.3	You didn't know how to talk to them about it	1	2	3	4	5
E7.4	You thought they would not understand	1	2	3	4	5
E7.5	You thought they would worry too much about you	1	2	3	4	5
E7.6	If the person was your partner, you thought they would stop having sex with you	1	2	3	4	5
E7.7	You thought they would stop being friendly	1	2	3	4	5
E7.8	You thought they would stop supporting you	1	2	3	4	5
E7.9	You thought they were too young to understand (in the case of children)	1	2	3	4	5

Interviewer read out: We would now like you to think about the first four **people (or up to 4) that you told about your HIV status excluding health-care workers.**

Please tell us about these experiences.

If you have told nobody GO TO E9

		Time 1	Time 2	Time 3	Time 4
E8.1	Initials of person or Name of group	N/A = 95	N/A = 95	N/A = 95	N/A = 95
E8.2.1	How is _____ related to you? (See codes for B.11 in household codes).	N/A = 95	N/A = 95	N/A = 95	N/A = 95
E8.2.2	Where do/did they live at the time you disclosed to them?				

Codes	In household	1

E8.2.2	Not in household, but in neighbourhood	2
	Outside neighbourhood, but in Cape Town	3
	In household, outside Cape Town	4
	Other (specify)	5

E8.3	What was their gender?	Male	1		1		1		1			
		Female	2		2		2		2			
		Not Applicable	95		95		95		95			
E8.4	About when did you tell them about your HIV status?	Month (01-12)		99		99		99		99		
		Year (4 digits)		9999		9999		9999		9999		
E8.5	Where you sick at this time?		YES 1	NO 2	YES 1	NO 2	YES 1	NO 2	YES 1	NO 2		
E8.6	What was your CD4 count at the time? (WRITE NUMBER)											
			DK	9999	DK	9999	DK	9999	DK	9999		
E8.7*	**How would you say your health was at the time you disclosed?** If 10 is the healthiest you have been in your life, what score would you give for how you felt: **(show card)**		10		10		10		10			
			9		9		9		9			
			8		8		8		8			
			7		7		7		7			
			6		6		6		6			
			5		5		5		5			
			4		4		4		4			
			3		3		3		3			
			2		2		2		2			
			1		1		1		1			
THINK OF THE PERSON YOU HAVE JUST TOLD ME ABOUT, HOW IMPORTANT WERE THE FOLLOWING REASONS? **(Show card)**			Person 1 (Read out Initials)		Person 2 (Read out Initials)		Person 3 (Read out Initials)		Person 4 (Read out Initials)			
E8.8* ARV04	You wanted to share your problems by talking to him/her	Not important	1		1		1		1			
		Slightly important	2		2		2		2			
		Important	3		3		3		3			
		Very important	4		4		4		4			
		Extremely important	5		5		5		5			
E8.9* ARV04	You wanted to educate him/her about HIV	Not important	1		1		1		1			
		Slightly important	2		2		2		2			
		Important	3		3		3		3			
		Very important	4		4		4		4			
		Extremely important	5		5		5		5			
E8.10* ARV04	You were sick and needed support	Not important	1		1		1		1			
		Slightly important	2		2		2		2			
		Important	3		3		3		3			
		Very important	4		4		4		4			
		Extremely important	5		5		5		5			
E8.11*	You needed	Not important	1		1		1		1			

ARV04	his/her help	Slightly important	2	2	2	2
		Important	3	3	3	3
		Very important	4	4	4	4
		Extremely important	5	5	5	5
E8.12* ARV04	You trusted him/her to keep it a secret	Not important	1	1	1	1
		Slightly important	2	2	2	2
		Important	3	3	3	3
		Very important	4	4	4	4
		Extremely important	5	5	5	5
E8.13* ARV04	To decrease stigma (to make him/her realise that people with HIV were normal people like you)	Not important	1	1	1	1
		Slightly important	2	2	2	2
		Import-ant	3	3	3	3
		Very important	4	4	4	4
		Extremely important	5	5	5	5
E8.14* ARV 04	You wanted to protect him/her from possible infection	Not important	1	1	1	1
		Slightly important	2	2	2	2
		Important	3	3	3	3
		Very important	4	4	4	4
		Extremely important	5	5	5	5
E8.15*	You had no choice	Not important	1	1	1	1
		Slightly important	2	2	2	2
		Important	3	3	3	3
		Very important	4	4	4	4
		Extremely important	5	5	5	5
E8.16	What was his/her reaction?	Positive	1	1	1	1
		Negative	2	2	2	2
		Indifferent	3	3	3	3
E8.17	Are you glad that you told him/her?	Yes	1	1	1	1
		No	2	2	2	2
		Don't' know	99	99	99	99

Involuntary Disclosure

We would now like you to think about all the people that you did not personally tell about your HIV status, but who know your status. Please tell us their initials.

Please think of first 4 people to find out your HIV status (OR up to 4) and tell us about these experiences.

IF NOT APPLICABLE SKIP TO F.1

All new questions			Time 1	Time 2	Time 3	Time 4
E9.1	Initials					
			N/A = 95	N/A = 95	N/A = 95	N/A = 95
E9.2	How is _____ related to you? (See codes for B.11 in household codes).					
			N/A = 95	N/A = 95	N/A = 95	N/A = 95
E9.3	What was their gender?	Male	1	1	1	1

		Female	2		2		2		2			
E9.4	About when did they find out about your HIV status?	Month (01-12)										
		Year (4 digits)										
E9.5	Where you sick at this time?		YES	NO	YES	NO	YES	NO	YES	NO		
			1	2	1	2	1	2	1	2		
E9.6	What was your CD4 count at the time?			DK 9999		DK 9999		DK 9999		DK 9999		
E9.7*	**How would you say your health was when this person found out you were HIV positive?** If 10 is the healthiest you have been in your life, what score would you give for how you felt: **(show card)**		10		10		10		10			
			9		9		9		9			
			8		8		8		8			
			7		7		7		7			
			6		6		6		6			
			5		5		5		5			
			4		4		4		4			
			3		3		3		3			
			2		2		2		2			
			1		1		1		1			
E9.8	What was their reaction?	Positive	1		1		1		1			
		Negative	2		2		2		2			
		Indifferent	3		3		3		3			
E9.9	How did they find out?											
E9.10	Are you glad that they know your HIV status?	Yes	1		1		1		1			
		No	2		2		2		2			
		Indifferent	3		3		3		3			

Appendix D: Instructions for Bodymapping[74]

1. Choose a partner.
2. Draw carefully around your partner's body with a coloured pen on a big piece of cardboard.
3. When you are finished drawing your partner ask your partner to draw around your body on the same piece of cardboard in a different colour. The two body shapes should overlap each other with one looking like a shadow.
4. Repeat the exercise on another piece of cardboard so your partner has his/her own body map to work on with you as the shadow.
5. Write your name and where and when you were born on the cardboard. Write this nice and big in a place outside of your outline.
6. Choose a colour to represent you and paint around the outline of your body.
7. Choose another colour and colour in the outline of your partner everywhere they are outside the outline of your body.
8. Discuss what your partner's shadow might mean to you. The following questions might help:
   - Has there ever been somebody in your life who has given you support through happy and sad times?
   - Which of you ancestors might this shadow be? Write their name somewhere next to the shadow and write something about this person and how they influence your life.
9. Paint your hands and feet using a sponge or paint brush and stamp them on your body map where your hands and feet are. Wash your hands and feet in the basin of water.
10. When you are feeling down or depressed, where in your body do you feel your emotional pain? Mark these places.
11. What part of your body gives you strength to overcome times of struggle? Feel where your place of personal power in your body is. Mark this place.
12. Choose a symbol to represent you. The symbol should represent your strengths and weaknesses. It could be a plant, an animal or an object. It can be anything that has meaning for you. It could also be a combination of a few symbols. Paint or draw the symbol onto your body map where you marked your place of personal power.
    - Some people have drawn Table Mountain representing their ties to Southern Africa.
    - Others have drawn a fruit or vegetable. and
    - Some have drawn farm animals symbolising how their strength lies in the Eastern Cape.
13. Everyone in the workshop can now share their symbols of personal power. The following questions might help to get people talking.
    - What have you drawn?
    - Why did you choose that particular symbol?
    - How does that symbol represent who you are?
    - Share a story from some time in your life which explains the symbol you have chosen.
14. Draw a five-minute self-portrait on your body map.
15. Close your eyes for one minute and try remembering your first memory. Somewhere on your body map paint/draw a picture of your first memory and describe it in a few words next to the picture.
16. Now close your eyes and imagine your future. Draw/paint this future somewhere on the body map.
17. You must now think about your physical body and your skin. Your body records all the marks that represent stories that have happened in your life. Notice all marks, birthmarks, beauty marks, scars, stretch marks, moles, pimples, rashes and wrinkles and laughter lines on your body. Draw these marks onto your body in the correct places. Next to the mark write something about how it came to be there.

[74] Further details of bodymapping and other psychosocial support tools for use in HIV support groups can be found at http://www.cssr.uct.ac.za/sites/cssr.uct.ac.za/files/Mapping%20Our%20Lives%20Manual%20%20-%20April%202007.pdf

18. Feel where else in your body, underneath the skin you feel strong emotion, joy or pain. Maybe you have had an operation or some of your organs have been damaged for some reason. Mark these places using colours and patterns.
19. Have you had TB in your lungs? Do you have heart or liver problems? Which of the organs in your body tell a story? Find an anatomical drawing to use for reference if you don't know what the organ looks like. Write next to your body outline what happened there and when.
20. You can also show emotion on your body maps. Draw places on your body where you feel different emotions and write a sentence explaining each one.
21. We all get sick, but some illnesses are worse than others. Some things in our lives make it easier or more difficult for us to get sick. In pairs or small groups discuss this and if you like you can write it on your body maps.
22. Talk about your last illness experience in small groups or pairs. (This exercise is optional depending on the group). The following questions might help:
    - How long ago was this?
    - How did you know you were ill?
    - Did you tell anyone that you were not feeling well? How did they react?
    - Where you able to carry on with your normal responsibilities while you were sick?
    - How did you know what to do?
    - Did you take any medicine? Where did it come from?
    - Did you have to pay any money to get well? Where did this money come from?
    - Do you think you should have done anything differently?
23. Some sicknesses are very common and others are not. Think about yourself, your family and your community. This exercise encourages discussion about HIV/AIDS together with other illnesses. In a large group discuss the following questions:
    - Which illnesses would you say are very common?
    - Which illnesses would you say are very rare?
    - Which illnesses do you and your family fear most? Why?
    - Which illness do you and your family fear least? Why?
    - Would any of these illnesses prevent people from speaking to you or treating you normally? Which? Why? How?
24. Ask yourself how HIV has affected your body? Has HIV left scars? What has happened to your skin? What opportunistic infections have you experienced and what did you do to heal yourself?
25. This is your body map so feel free to add any other details, colours or patterns that have special meaning to you. Think of a slogan for your body maps that means something special to you. Some examples from past workshops are:
    - Be wise. Condomise.
    - Love yourself. Love Life.
    - One way. One heart.
    - Knowledge protects.
26. Prepare a 5-10 minute presentation of your body map. How do you feel about your body map? What stories does it tell? What have you learnt about yourself and your health?